

Caregiver Assessment (Part I of II): Why and What Should We Assess?

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Introduction

- **Families provide the majority of care and support for the millions of adults in need of assistance.**
- **The number of family caregivers is steadily increasing: estimated 44 million in 2003 vs. 48.9 million in 2009.^{1, 2}**
- **Caregivers have multiple, varied, and serious unmet needs.**
- **Assessment and care planning is fundamental to meeting the needs of family caregivers.**

Objectives

To describe:

1. The critical issues relevant to assessing and meeting the needs of family caregivers.
2. The processes and products that are essential to successful caregiver assessment.
3. Techniques and strategies for conducting assessments and creating an effective care plan.
4. The future direction of caregiver assessment.

1) Assessing and meeting the needs of family caregivers

Who are family caregivers and what do they do?

- Relatives or friends (broadly defined) who provide assistance or support to an adult with a chronic or disabling physical or cognitive condition.
- They provide emotional, financial, physical, and hands-on support.
- Self identification as “caregiver” can be problematic.



1) Assessing and meeting the needs of family caregivers (cont'd)

Why should we assess family caregivers?

- They play a critical role in our health and long-term care systems.
- They are a vulnerable group who are at-risk for multiple and serious physical and mental health conditions.
- To determine if the caregiver is able/willing to assume care responsibilities and the care recipient is willing to accept care.



1) Assessing and meeting the needs of family caregivers (cont'd)

Why should we assess family caregivers?

- Well-designed assessments should lead to a targeted care plan that can improve outcomes for caregivers and care recipients.
- To help them gain access to appropriate services and follow-up support tailored to their specific and changing needs.
- To support the caregiver's choice to continue to provide care in the home and in other settings.



2) What processes and products are essential to caregiver assessment?

Process

- Collect information about the care situation to identify a caregiver's specific challenges, needs, resources, and strengths.
- A conceptual framework can provide structure and direction for types of questions to be asked.
- Structure and location of the assessment varies: in-person, telephone, self-administered, electronic, structured interview vs. informal conversation, at home vs. another private setting.

2) What processes and products are essential to caregiver assessment (cont'd)?

Process (cont'd)

- Family-centered perspective that captures the needs and preferences of the caregiver and the care recipient.³
- Multi-dimensional, culturally sensitive, and context relevant.
- Assessment staff must be well-trained and understand the caregiving process, its benefits and consequences.
- Purpose of assessment must be clear: identify caregiver(s), program eligibility, care planning options, change in caregiver's or care recipient's status or situation.

2) What processes and products are essential to caregiver assessment (cont'd)?

Process (cont'd)

- Important to assess the care recipient's eligibility to receive services that support the caregiver.
- Measures must have good psychometric properties.
 - Are you assessing what you think you're assessing?
- No need to reinvent the wheel.



2) What processes and products are essential to caregiver assessment (cont'd)?

Process (cont'd)

- Screening ≠ Assessment
 - Identifies at-risk caregivers.
 - Assesses “readiness”.
 - Should occur before or in conjunction with assessment.
- Assessment ≠ Reassessment
 - Periodic reassessment is strongly recommended.
 - Quick phone call with a few targeted questions.
 - Identify changes in care situation.
- Questions must align with the purpose and goals of the screening, assessment, and reassessment.



2) What processes and products are essential to caregiver assessment (cont'd)?

Products

- **Plan of care that draws upon seven targeted domains:**
 1. Context
 2. Caregiver's perceptions of care recipient's health and functioning
 3. Caregiver's values and preferences
 4. Caregiver's well-being
 5. Consequences and rewards of providing care
 6. Caregiver's skills and abilities to provide needed care
 7. Resources available to the caregiver³

2) What processes and products are essential to caregiver assessment (cont'd)?

Products (cont'd)

- Care plan that clearly outlines eligibility and options for service, potential informal support, maintaining optimal health, and setting future goals.
- Services and support must be consumer directed and family focused.³
- Goal is for outcomes to be clearly measured in order to determine change: self-care, mental and physical health.
- Caregiver assessment and support are critical to ensuring positive outcomes and continuity of care for the care recipient too!

3) Techniques and strategies for conducting assessments

Barriers / challenges to assessment



- Reimbursement is inconsistent.
- Government and other third-party payers do not always reimburse for CG assessment.³
- Lack of skilled workforce trained to understand the needs of the family caregiver.
- Caregiver does not self identify as caregiver.
- Confidentiality: Unethical to talk with caregiver if care recipient (client) refuses to release contact information.
- Balancing best interests of caregiver with best interests of care recipient.

3) Techniques and strategies for conducting assessments (cont'd)

- **Family Consultants at California's Caregiver Resource Centers (CRCs)**
 - Background
 - Not case managers
 - Caregiver is client
- **Process of Assessment**
 - Home visit or phone assessment
 - Tools
 - Caregiver Action Plan and 1-month follow up
 - Reassessments
 - Closing clients



3) Techniques and strategies for conducting assessments (cont'd)

- **Cultural considerations**
 - Adapting assessment to be appropriate to family culture
 - LGBT inclusive language
 - Translating assessment and using interpreters
- **Client focused**
 - Goals of client vs. goals of agency assessing
 - Assessment as an intervention

3) Techniques and strategies for conducting assessments (cont'd)

- Massachusetts
- Washington
- American Medical Association
- California's CRCs
- FCA Caregivers Count Too! Tool kit



4) Using an assessment to create an effective care plan

List of available services that match caregiver's unmet needs

Available services	Caregiver's unmet need
Individual counseling	Caregiver rates high on measure of depression or anxiety
Educational classes or support group	Caregiver scores low on knowledge of diagnosis and symptoms of dementia
In-home respite	Caregiver notes she's "stuck at home all day" and rates high on scale of care "overload" or being "trapped" in caregiver role
Chore services	Caregiver rates high on needing help with household chores
Neighbor to walk with	Caregiver has barriers to self-care (not exercising, missing doctor's appointments)

4) Using an assessment to create an effective care plan (cont'd)

Connection between caregiver and care recipient assessments

- Best case scenario: same person assesses both the caregiver and care recipient together or separately as appropriate.
- Share information across professionals and service settings if coordinated assessment is not possible.
- Effective assessment and subsequent care planning and reassessment can improve outcomes for caregivers and care recipients.

5) Update on Caregiver Assessments

- Texas
- New Jersey



- **Selected caregiver assessment measures:
A resource for practitioners (2nd edition)**
 - Where are the gaps in available measures?

The goal of assessment.....

“The goal of assessment should be to help the person in need of care and the family providing the care achieve the best possible quality of life in accordance with their values, needs, resources, and preferences.”

~ Lynn Friss Feinberg, MSW
Senior Strategic Policy Advisor
AARP Public Policy Institute

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References

¹ National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S.: Findings From the National Caregiver Survey (2004)*, Washington, DC.

² National Alliance for Caregiving and AARP (2009). *Caregiving in the U.S. 2009*, Washington, DC.

³ Family Caregiver Alliance (2006). *Caregiver assessment: Principles, guidelines, and strategies for change (Vol. 1)*. San Francisco, CA.

⁴ Family Caregiver Alliance (expected 2012). *Selected caregiver assessment measures: A resource inventory for practitioners (2nd edition)*. San Francisco, CA.