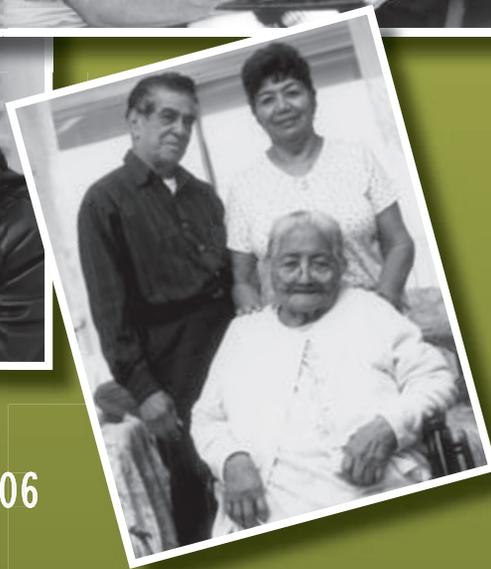


REPORT from
A National Consensus Development Conference

Caregiver Assessment: Principles, Guidelines AND Strategies FOR Change

VOLUME I



APRIL 2006



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving



About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Visit www.caregiver.org.

The Robert Wood Johnson Foundation provided the primary financial support for the National Consensus Project *for* Caregiver Assessment. Other funders include the Archstone Foundation and The California Endowment.

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Preface

This report arises from an invigorating landmark event: The National Consensus Development Conference *for* Caregiver Assessment. The National Center on Caregiving at Family Caregiver Alliance (FCA) convened this forum to fill a major gap in policy and practice.

A large and growing body of research shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk for physical, emotional and financial problems. Systematic assessment of people with chronic or disabling conditions now occurs routinely in medical, health and social service settings. However, assessment of family caregivers' needs is rare.

Thus, we invited leaders and stakeholders to a working conference to advance policy and practice on behalf of family caregivers. From September 7-9, 2005 in San Francisco, 54 recognized experts in caregiving, health and long-term care issues—scholars, practitioners and public officials—deliberated intensively about caregiver assessment. They brought balanced, objective and knowledgeable attention to the issue. We hoped to reach consensus on principles and guidelines for caregiver assessment while building common ground among leaders in the field. We exceeded our expectations.

Volume I, *Caregiver Assessment: Principles, Guidelines and Strategies for Change*, reflects the professional consensus achieved at this conference: the importance to policy and practice of systematically assessing a caregiver's own needs in health care and in home and community settings; fundamental principles and practice guidelines for caregiver assessment applicable to a range of practitioners in a variety of settings; and strategies and actions to advance caregiver assessment as a basic component of practice.

Volume II, *Caregiver Assessment: Voices and Views from the Field*, provides four background papers and two personal accounts. Together they portray key issues in caregiver assessment and illustrate the impact of caregiving at home on the family members who provide the care and support. Both volumes are available online at www.caregiver.org, or as printed reports, available from Family Caregiver Alliance.

Embracing a family-centered perspective requires a fundamental change of thinking in policy and practice. Looking ahead, we hope this report fosters the adoption of the consensus principles and guidelines and serves as a catalyst to strengthen America's caregiving families.

Kathleen A. Kelly
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Acknowledgements

This consensus report reflects a collaborative process involving many individuals and organizations. The National Center on Caregiving at Family Caregiver Alliance (FCA) is deeply grateful to our funders for their commitment to this important effort and their financial support that made this project possible: The Robert Wood Johnson Foundation, with additional assistance from the Archstone Foundation and The California Endowment. Jane Isaacs Lowe, our project officer at the Robert Wood Johnson Foundation, offered vital help and encouragement.

Our national advisory committee provided invaluable assistance, dedication, guidance and expertise in designing the consensus development conference and throughout the project: David Bass, Adrienne Dern, Virginia Dize, Laura Gitlin, Myra Glajchen, Robyn Golden, Carol Levine, Katie Maslow, Susan Reinhard and Lorie Van Tilburg. The 54 national and state experts who accepted our invitation to participate in the consensus development conference deserve our deep appreciation. They gave us the benefit of their experience and diverse perspectives during the two-day working conference and provided thoughtful comments on the draft principles, practice guidelines and change strategies for caregiver assessment that are the focus of this consensus document.

We thank the following FCA staff and consultants who made significant contributions to the successful design and implementation of the conference itself and this final report. Superb facilitation from Laura Peck, overall conference facilitator, allowed us to reach consensus on the key issues; Beth Logan, conference logistics coordinator and Lana Sheridan, administrative assistant, helped make the conference run smoothly and effectively; Laura Byrne, Kris Coffey, Cara Goldstein and Susan Poor served ably as work group recorders; and Bonnie Lawrence and Melania Jusuf contributed to the production of this report. Special appreciation goes to Carol Van Steenberg for her skilled editorial assistance, work group facilitation and ongoing support throughout the project.

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Caregiver Assessment: Principles, Guidelines and Strategies for Change

Volume I

Overview

Achieving quality of care for people with chronic or disabling conditions depends on embracing a family-centered perspective. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address family caregivers' needs too. Establishing caregiver assessment as a basic component of practice across care settings—with formal recognition of caregiving families and the goal of strengthening them—calls for a fundamental change of thinking in policy and practice. This report from the National Consensus Development Conference *for* Caregiver Assessment provides the foundation for such change.

For America's families, the challenges and pressures of family caregiving are a reality of daily life. Today, family caregivers monitor chronic and sometimes acute medical conditions as well as provide long-term care at home. Although family and friends (known as informal caregivers) are the backbone of our health and long-term care system, the significance of their role, and their own care-related strain and compromised health, is often overlooked.

A 25-year body of research shows that family members who provide care to persons with chronic or disabling conditions are themselves at risk. Emotional, physical and financial problems arise from the complexities and strains of caring for frail or disabled relatives, especially when the care is for a person with dementia. These burdens and health risks can impede the caregiver's ability to provide care, lead to higher health care costs, and affect their quality of life and those for whom they care. Thus, a key concern is how to “keep families on the job.”¹

The Need for Consensus

The value of systematic assessment of family caregivers' needs in health care and in home and community-based long-term care (LTC) settings has gained increased attention in recent years and is now clearly on the public policy agenda.² This interest stems, in part, from the recognition of the fundamental need to improve direct supports for family caregivers and to focus on outcomes and quality of care.³⁻¹⁰ Indeed, the well-being of the caregiver is often key to the care recipient getting the help needed; it is also frequently a deciding factor in determining whether an individual can remain at home or must turn to more costly nursing home care.

Yet, a major gap exists between research and practice. Even though understanding the role, multiple stressors and particular situation of the family caregiver is viewed as essential to any care plan developed for the care recipient,¹¹⁻¹³ few federal and state home and community-based services (HCBS) programs uniformly assess the family caregiver's well-being and needs for support. Some HCBS programs focus specifically on the care recipient; others (like the Older Americans Act's National Family Caregiver Support Program) have an explicit charge to address caregiver needs; and still others view both the care recipient and the caregiver as the "client population."¹⁴ Nonetheless, state officials that administer these HCBS programs recognize the value of uniformly assessing caregiver needs, using the information to inform policy and practice, and the importance of practice guidelines and training in this area.^{15, 16}

A recognized means for bridging the gap between research and practice is the development and dissemination of consensus guidelines.¹⁷⁻¹⁹ Professional consensus on the central importance of caregiver assessment, with fundamental principles and practice guidelines, is key to advancing the family-centered approach, effectively supporting caregivers and improving quality of care. This report furthers that goal.

Organizational Structure of the Consensus Conference

The National Consensus Development Conference *for* Caregiver Assessment brought together widely recognized leaders in health and long-term care, with a variety of perspectives and expertise, to advance policy and practice on behalf of family and informal caregivers. The Family Caregiver Alliance's (FCA) National Center on Caregiving designed and convened this conference, held September 7-9, 2005, in San Francisco. The Robert Wood Johnson Foundation provided primary support for this conference with additional support from the Archstone Foundation and The California Endowment. A National Advisory Committeeⁱ guided the project, including the nomination of conference participants.

ⁱ See page iv for a list of National Advisory Committee members.

The conference had two goals:

1. To generate principles and guidelines for caregiver assessment; and
2. To build common ground among leaders committed to innovation, experimentation and the systematic generation of new knowledge.

Four background papers (included in Volume II of this report, *Caregiver Assessment: Voices and Views from the Field*, and available at www.caregiver.org) were commissioned for the conference. Together they provided research, practice and policy perspectives, and an international comparison of approaches to caregiver assessment across six countries.

- ◆ *Assessment of Family Caregivers: A Research Perspective* by Steven H. Zarit, PhD (Professor, Department of Human Development and Family Studies, The Pennsylvania State University).
- ◆ *Assessment of Family Caregivers: A Practice Perspective* by Nancy Guberman, MSW (Professor, School of Social Work, University of Quebec in Montreal).
- ◆ *Assessment of Family Caregivers: A Public Policy Perspective* by Katie Maslow, MSW (Associate Director, Quality Care Advocacy at the Alzheimer's Association); Carol Levine, MA (Director, Families and Health Care Project at the United Hospital Fund) and Susan Reinhard, PhD, RN (Professor and Co-Director, Rutgers Center for Health Policy).
- ◆ *Assessment of Family Caregivers: An International Comparison Across Six Countries* by Anne Montgomery, MS (Health Policy Associate at the Alliance for Health Reform).

The 54 participantsⁱⁱ included leading scholars, federal and state policymakers, family caregivers, service providers and advocates in health and long-term care for older people, adults with disabilities and their families. In plenary and small-group sessions participants met over a two-day period and discussed, framed and refined the issues.ⁱⁱⁱ Conferees were organized into four working groups, each designed to address an essential component needed to further caregiver assessment in policy and practice: 1) domains and outcomes; 2) structure and implementation; 3) practice patterns, and education and training; and 4) policy issues.

ⁱⁱ See Appendix A for a list of conference participants.

ⁱⁱⁱ See Appendix B for Conference Program Agenda.

Through the consensus development process^{iv}, the conference achieved:

- ◆ Recognition of the importance of systematically assessing a caregiver's own needs, as part of policy and practice in health care and in HCBS settings.
- ◆ Consensus on fundamental principles and practice guidelines that apply to a range of practitioners, providers and care managers in a variety of settings (e.g., home, hospitals, community-based programs).
- ◆ Identification of change strategies and actions to advance caregiver assessment as a basic component of practice.
- ◆ Heightened interest among the invited leaders to take steps to promote caregiver assessment.

Purpose and Organization of Report

This report is intended to:

1. Stimulate adoption of these principles and guidelines across settings (home, hospital, physician offices, community-based programs);
2. Facilitate implementation of the change strategies and actions to further formal recognition of caregiver needs in health and HCBS settings;
3. Foster collaboration with key national organizations to advance the work of this consensus conference; and
4. Promote future research and evaluation.

The next sections of this report provide an explanation of working definitions used in the consensus conference; a synthesis of the background and significance of family care and caregiver assessment; the principles, guidelines and change strategies for which there is consensus; and lastly, conclusions. The resounding theme across the areas of consensus is the importance of promoting systematic assessment of caregivers' needs as part of routine practice. Throughout this paper are quotations from conferees to illustrate the conversations behind the consensus that emerged.

^{iv} See Appendix C for a description of the process for developing consensus.

Working Definitions

Family Caregiver is broadly defined and refers to 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. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.

Care Recipient refers to 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. These tasks may include managing medications, transportation, bathing, dressing and using the toilet. The person needing assistance may also require primary and acute medical care or rehabilitation services (occupational, speech and physical therapies).

Caregiver Assessment refers to a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It 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, and seeks to maintain the caregiver's own health and well-being.

Background and Significance

Are we ready to make the paradigm shift that moves caregivers from the shadows to the forefront of policy, agency and worker attention?

—Nancy Guberman
Professor, School of Social Work
University of Montreal in Quebec

The Pivotal Role of Family Care

Family care is the most important source of assistance for people with chronic or disabling conditions who require long-term care (LTC). Although policymakers and health care providers frequently associate LTC with nursing homes, that perception mischaracterizes the reality of where most LTC is provided and by whom.²⁰ Nearly 10 million Americans need long-term care in the U.S.²¹ Among adults who need long-term care services and supports, most—80 percent—live at home or in community settings, *not* in nursing homes.²²

More than three-quarters (78%) of adults (age 18+) who receive LTC at home get *all* their care exclusively from unpaid family and friends, mostly wives and adult daughters. Another 14 percent receive some combination of family care and paid assistance; only eight percent rely on formal care alone.²³ Recent research suggests that among community-dwelling older people (age 65+) with disabilities, the use of formal, paid care has declined while sole reliance on family caregivers has increased.²⁴

An estimated 44 million adults (age 18+) provide unpaid assistance and support to older people and adults with disabilities who live in the community.²⁵ In 2000, informal (i.e., unpaid) caregiving by family and friends had an estimated national economic value of \$257 billion annually, greatly exceeding the combined costs of nursing home care (\$92 billion) and home health care (\$32 billion).²⁶ Without family and informal caregivers, spending for LTC services would be much higher than it is now.²⁷

Policymakers are aware of family caregiving now. It's on their minds, it's on their radar screen. The main, accepted recognized goal is "to keep them on the job." Family and friends [informal caregivers] are important, we can't do it without them, we have to keep them "on the job." Family caregiver assessment is obviously important in that context.

—Katie Maslow
Associate Director, Quality Care Advocacy
Alzheimer's Association

Caregiving has been, is now and will continue to be central to American family life. Today family care for people with chronic or disabling conditions is at a tipping point, however. Several converging factors make family caregiving a public health issue of critical national significance today:

- ◆ Medical advances, shorter hospital stays, limited discharge planning, and expansion of home care technology have transferred the cost and responsibility for the care of frail elders and persons with disabilities onto families. Family members are now asked to assume a health management role in the home and carry out medical tasks that traditionally were carried out by health care providers (e.g., bandaging and caring for wounds, operating pumps and machines at the bedside, administering multiple medications), with little or no preparation, training or support.²⁸
- ◆ The dramatic demographic shift to an aging population, with an estimated one in five Americans aged 65 and older by 2030, is prompting policymakers to closely examine the financing and service delivery of our health and LTC systems. Important issues being examined include the escalating costs of care, fragmentation in HCBS, shortage of frontline and direct care workers, lack of coordination and continuity of health care, and the need to improve quality of care in all settings. These central issues affect individuals with chronic or disabling conditions and their family members. Often, a family caregiver serves also as the “point person” to identify, access and coordinate information, health care and home and community-based services.
- ◆ Changes in family life (e.g., more women in the workplace, more geographic dispersion) impact the care recipient and the caregiver. Today's family caregivers juggle work, caregiving and other family responsibilities. With older people less likely now to have family close by than in the past,²⁹ long-distance caregiving is a mainstay of life for many Baby Boomers who are in the labor force and care for their aging parents.³⁰

- ◆ The policy direction to shift from institutional toward more home and community care—what most Americans value and want—depends greatly on family caregiving.³¹ Adults with disabilities—whether old, middle aged or young—need a range of services and supports, most of which are provided by family caregivers.^{32, 33}

Although caregiving is usually undertaken willingly and may bring deep personal satisfaction, it frequently takes a great emotional, physical and financial toll on the family caregivers themselves.

It was on my mom that I changed my first diaper. It was in her nursing home because there was no staff available. I prayed with all my might that I would not compromise her dignity. I prayed with all my might that someone, somewhere would one day tell other sons that they may have to change their own mother's diaper.

—Dan Ahern
Former Family Caregiver

A body of research over the past 25 years shows family caregivers to be a vulnerable and at-risk population that the health and long-term care system neglects.

- ◆ Family caregivers receive little support and assistance themselves, despite psychologically stressful and physically exhausting tasks (e.g., use of high-tech medical equipment in the home, managing complex medication schedules, supervising behavior of persons with dementia, accessing and negotiating health care and home and community-based services).^{34–37}
- ◆ Family caregivers face health risks and serious illness^{38–40} (e.g., heart disease,⁴¹ hypertension,^{42, 43} poorer immune function,^{44, 45} slower wound healing,⁴⁶ lower perceived health status,^{47–50} increased use of psychotropic drugs⁵¹), emotional strain and mental health problems (especially depression).^{52–58}
- ◆ Evidence suggests that some caregivers are at increased risk of mortality.^{59, 60}
- ◆ Family caregivers face workplace issues,^{61–65} financial insecurity and financial burdens.^{66–68} Caregiving is often costly (to both employers and employees) in terms of lost wages and impacts on job productivity.^{69, 70}
- ◆ Out-of-pocket medical expenses for a family caring for someone who needs help with everyday activities (e.g., bathing, dressing) are more than 2.5 times greater than for a non-caregiving family (11.2% of income vs. 4.1%).⁷¹

Sustaining family caregivers and their ability to provide care at home or in the community is crucial to our health and LTC system. A key concern is that the continued reliance on family caregivers, without better recognition of their own support needs, could negatively affect the ability of family caregivers to provide care in the future and result in even greater emotional, physical and financial strains. This negative impact on the caregiver likely would affect quality of care and the quality of life of the care recipient and the rest of the family. Research has shown that unrelieved caregiver depression, exhaustion, financial concerns and other care-related strain are major contributing factors to institutionalization, often resulting in higher public expenditures for nursing home costs.^{72–76}

One Sunday morning my dad called and apologized for having to ask if I wouldn't mind driving him to the hospital to get his head stitched up. He was so exhausted from getting up several times every night to keep an eye on my then-wandering mom who had Alzheimer's disease, that when he finally dozed off he had a nightmare, fell out of bed and cut his head on the nightstand.

—Dan Ahern
Former Family Caregiver

The Case for Assessment of Family Caregivers

9

The implications of research as well as principles of good practice unequivocally support the premise that assessing caregivers is a necessary and essential part of working with older clients in virtually every setting.

—Steven H. Zarit, PhD
Professor, Department of Human Development and
Family Studies
The Pennsylvania State University

Moving from tacit acknowledgement to explicit recognition of what family caregivers do, why they do it and what they need also may help to improve the quality of community-based long-term care services.

—Anne Montgomery
Health Policy Associate
Alliance for Health Reform

Systematic assessment of people needing care due to chronic or disabling conditions is now a core element of practice in medical, health and social service settings. In contrast, assessment of the family caregiver is not routinely carried out in

practice to determine what help the caregiver may need as distinct from, but related to, the needs of the care recipient.^{77,78} Nor does caregiver assessment typically function as a tool to understand the needs and capacities of the family and improve the quality of care for the care recipient.

I have been a caregiver for almost 16 years. My husband was grievously injured, both in body and mind, in an automobile accident from which I walked away with only a broken heart. Not for me the slow dawning of caregiver-hood, the gradual assumption of responsibilities as an aging parent declines in frailty or dementia. I was thrown into the black hole of long-term chronic care for my life partner, my lover, my best friend, and my best writing critic. And there I remain. In all those years through crises, major and minor, intensive care, surgeries, rehab, more surgeries, more rehab, short-term home care, I've never had a formal caregiver assessment, a discussion about my needs, my strengths, my weaknesses, my health, my well-being, my finances, my job, my other family responsibilities.

—Carol Levine
Family Caregiver and Director
Families and Health Care Project, United Hospital Fund

Practitioners must consider not only how the family caregiver can help the care recipient, but how the service provider must help the family.⁷⁹ The success of most care plans – from hospital discharge to everyday care in the home – often rests on the shoulders of the family caregiver. If the family caregiver becomes sick or can no longer cope with caregiving tasks, the care recipient suffers. If the strain on a caregiver becomes too great, care in the home may be seriously compromised and can lead to nursing home placement. Therefore, effective outcomes in care settings (e.g., hospitals, home, community-based care) depend upon knowing the needs and risks of both the care recipient and the family caregiver. In sum, the complexities of caregiving, the varied tasks performed and the oftentimes negative physical, emotional and financial effects of providing family care, point to making systematic caregiver assessment an essential component of policy and practice in health care and home and community-based care.

Consensus on basic principles and practice guidelines for caregiver assessment is necessary to accelerate improvements in policy and practice. Policymakers, program administrators, and health and social service practitioners are encouraged to incorporate these principles and guidelines in their work.

Policy changes and further research should be pursued, based upon these consensus points, to advance the effective development and delivery of caregiver assessment tools and protocols across care settings (i.e., for use in health care facilities, home care situations and community-based agencies). It is intended that this collective effort to crystallize consensus will serve as a catalyst for national change to support families in their caregiving role.

Fundamentally, policymaking tends to be its own kind of consensus process that balances political, economic and other interests. Thus, it often evolves more or less gradually and incrementally. We are in an era when health information technology is beginning to make gathering and analyzing information considerably easier; when research is being used increasingly in quality improvement efforts; and when consumers are being given signals to be more assertive about selecting health care providers and services. Caregiver assessment is compatible with these broad trends.

—Anne Montgomery
Health Policy Associate
Alliance for Health Reform

Fundamental Principles *for* Caregiver Assessment

Conference participants agreed upon a set of seven basic principles to guide caregiver assessment policy and practices:

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.
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.
4. Caregiver assessment should be multidimensional in approach and periodically updated.
5. Caregiver assessment should reflect culturally competent practice.
6. Effective caregiver assessment requires assessors to have specialized knowledge and skills. Practitioners' and 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.
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

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
Deputy Director, National Center on Caregiving
Family Caregiver Alliance

There is an overarching need to reduce redundancy and fragmentation across the care continuum and to embrace patient- and family-centered care.

—Laura Gitlin, PhD
Director, Center for Applied Research On Aging and Health
Thomas Jefferson University

1. General Considerations

- A. Public and private programs should recognize key dimensions of family caregiving:
- ◆ The unit of care is the care recipient and the caregiver. (This builds on the hospice and palliative care movement that has long embraced the patient/family as the unit of care.)⁸⁰
 - ◆ The caregiver is part of the care team and service plan.
 - ◆ Services should be consumer directed and family focused.
 - ◆ Caregiver assessment and support improves outcomes and continuity of care for the care recipient.
- B. The form, content and process for caregiver 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 and technological resources and capabilities all have to be considered; these vary by settings and existing service programs.

- C. The reasons for conducting a caregiver assessment need to be clear to both assessor and caregiver. These are:
- ◆ To identify the primary caregiver and other informal caregivers.
 - ◆ To improve caregiver understanding of the role and 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 caregiver.
 - ◆ To identify services available for the caregiver and provide appropriate and timely referral for services.
 - ◆ The process should include determining the care recipient’s eligibility for services that also help the caregiver.
- D. Assessment findings should be used in care planning and service interventions.
- ◆ Assessment is not an end in itself but should empower caregivers to make informed decisions and link caregivers with community services.
- E. Available information technology should be used to share assessment findings and make it easier for the caregiver to access help.

2. Who Should Be Assessed?

Ideally, all caregivers who come into contact with the health and social service systems should be assessed routinely as early as possible to involve them in care planning and to identify their own needs.

—Nancy Guberman
Professor, School of Social Work
University of Montreal in Quebec

- A. Any person who self-identifies as a family caregiver should be offered a screening, leading to an assessment as appropriate.
- B. Some families may require a group interview; others may need multiple individual interviews.
- C. When multiple caregivers are involved, conflict resolution may be necessary.

3. What Should Be Included in a Caregiver Assessment?

There is a happy medium, a sensible approach that will take caregivers through the critical issues and focus on the topics that are relevant.... If it's the right kind of assessment that addresses the main concerns that caregivers have, it will help everybody involved in the situation.

—Steven H. Zarit, PhD
Professor, Department of Human Development and
Family Studies
The Pennsylvania State University

A. Caregiver assessment should be driven by:

- ◆ A conceptual framework
- ◆ The service context and programs (e.g., focus of the intervention)
- ◆ Representation of subjective perceptions and preferences along with objective characteristics of the caregiver
- ◆ Factors affecting an individual's ability to assume a caregiving role: physical, emotional, cultural, educational and environmental, including the care recipient's ability to accept assistance.

B. Seven identified domains, and related constructs, are relevant. These are applicable across settings (e.g., home, hospital) but need not to be measured in every assessment. Domains and specific questions may differ for:

- ◆ Initial assessments compared to reassessments (the latter focus on what has changed over time)
- ◆ New versus continuing care situations
- ◆ An acute episode prompting a change in caregiving versus an ongoing need
- ◆ Type of setting and focus of services.

Recommended Domains and Constructs

Domains	Constructs
Context	<ul style="list-style-type: none"> ◆ Caregiver relationship to care recipient ◆ Physical environment (home, facility) ◆ Household status (number in home, etc.) ◆ Financial status ◆ Quality of family relationships ◆ Duration of caregiving ◆ Employment status (work/home/volunteer)
Caregiver's perception of health and functional status of care recipient	<ul style="list-style-type: none"> ◆ Activities of daily living (ADLs; bathing, dressing) and need for supervision ◆ Instrumental Activities of Daily Living (IADLs; managing finances, using the telephone) ◆ Psycho-social needs ◆ Cognitive impairment ◆ Behavioral problems ◆ Medical tests and procedures
Caregiver values and preferences	<ul style="list-style-type: none"> ◆ Caregiver/care recipient willingness to assume/accept care ◆ Perceived filial obligation to provide care ◆ Culturally based norms ◆ Preferences for scheduling and delivery of care and services
Well-being of the caregiver	<ul style="list-style-type: none"> ◆ Self-rated health ◆ Health conditions and symptoms ◆ Depression or other emotional distress (e.g., anxiety) ◆ Life satisfaction/quality of life
Consequences of caregiving	<ul style="list-style-type: none"> ◆ Perceived challenges <ul style="list-style-type: none"> • Social isolation • Work strain • Emotional and physical health strain • Financial strain • Family relationship strain ◆ Perceived benefits <ul style="list-style-type: none"> • Satisfaction of helping family member • Developing new skills and competencies • Improved family relationships
Skills/abilities/knowledge to provide care recipient with needed care	<ul style="list-style-type: none"> ◆ Caregiving confidence and competencies ◆ Appropriate knowledge of medical care tasks (wound care, etc.)
Potential resources that caregiver could choose to use	<ul style="list-style-type: none"> ◆ 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 (health care and service benefits, entitlements such as Veteran's Affairs, Medicare) ◆ Community resources and services (caregiver support programs, religious organizations, volunteer agencies)

4. When Should Assessment Occur?

We need to assess caregivers whenever the health, the well-being, or the safety of an older person depends upon an informal caregiver. We need that person's point of view to know what's needed.

—Steven H. Zarit, PhD
Professor, Department of Human Development and
Family Studies
The Pennsylvania State University

- A. A caregiver assessment process should be used at several points in time.
- ◆ Initial information about the caregiver's perspective should be obtained as early as possible when becoming a caregiver is apparent and the caregiver is ready, as shown by seeking advice or asking a question that indicates distress, need or “a call for help.”
 - ◆ Screening is distinct from assessment, and both are part of a multi-dimensional, staged process.
 - In partnership with the caregiver, screening should have the ability to branch and go deeper, in a logical sequence involving different professional disciplines where appropriate.
 - Screening should identify at-risk caregivers.
 - If the caregiver does not want to proceed with screening, information should be provided on how to get back in touch for assistance in the future.
 - ◆ Reassessment should be built into the process to identify any new challenges and to assess change over time in the caregiving situation:
 - Update information as often as needed.
 - Provide the caregiver with a contact to call upon if the situation changes.
 - Make a quick “check-in” call to the caregiver periodically (e.g., every three to six months) to ask “Has anything changed?” or “How are things going?”
- B. The opportunity for a caregiver assessment should be triggered through:
- ◆ Professional referrals—such as those from pharmacists, physicians, clergy, parish nurses, home care workers, Adult Protective Service and the courts
 - ◆ Self-referral

- ◆ Diagnosis of a medical condition
- ◆ Decreased functional status of caregiver or care recipient (e.g., no longer safe to leave care recipient alone)
- ◆ New patient, health plan enrollee or Medicare beneficiary
- ◆ Complaint from a care recipient
- ◆ Care transitions (e.g., from home to assisted living or nursing home, or from hospital to home)
- ◆ Caregiver workplace issues (performance, attendance problems)
- ◆ Concern from another family member or friend.

5. How and Where Should Caregiver Assessments Be Conducted?

You can't go in with a hidden agenda, like to see if the caregiver can really take care of the care recipient at home, so that you don't have to put formal services in place.

—Myra Glajchen, DSW
Director, Institute for Education and
Research in Pain and Palliative Care
Beth Israel Medical Center

- A. It should always be clear to the caregiver when an assessment is taking place. That is, it should be explained explicitly that information is being collected and that the primary purpose is to help the caregiver.
 - ◆ Some caregivers may find the term “assessment” objectionable, seeing it to suggest a test of their competency.
 - ◆ Calling the process an interview to obtain the family’s perspective or a “caregiver interview” may be preferable so long as the process and purpose are transparent.
 - ◆ Caregiver assessment should always be framed in the context of “I’d like to know how we could help.”
- B. Whenever possible, the caregiver’s preferences in conducting the assessment should be determined and accommodated.
 - ◆ Some caregivers want to know the questions beforehand or to do a self-screening first (online or otherwise); others do not.

- The location and time of day for conducting the assessment should depend upon the caregiver's situation and convenience, whether over the telephone (which may not be optimal), in the home (where the care recipient may be present), at the caregiver's place of employment, agency office, or online.

6. Who Should Conduct Caregiver Assessments?

You need to know what you know and what you don't know, and when to hand off to other people.

—Robyn Golden
Director of Older Adult Programs
Rush University Medical Center

- A. A range of professionals can conduct caregiver assessments (e.g., physicians, nurses, social workers, care managers).
 - ◆ Professional differences exist in the approach to assessment and these differences can be strengths that benefit the family.
 - ◆ Staying with the consumer focus can bridge professional differences.
 - ◆ Working as a team across professional disciplines allows for cross-fertilization so that the family comes out ahead.
- B. Assessors need to be trained in caregiver assessment and have the requisite abilities, knowledge and skills.

Recommended Knowledge, Abilities and Skills for Assessors

<i>Knowledge about...</i>	<i>Abilities to...</i>	<i>Skills for...</i>
Purpose of the assessment Self-determination versus safety issues Mental health, aging, life-span development issues Family systems perspective and conflict resolution Resources and brokering, building a community care support network Consumer-driven model, the importance of caregiver participation and the strengths-based perspective	Buy-in to purpose of assessment Listen and reflect Deal with emotional content Be sensitive to differences in framing questions around culture, religion, age, etc. Empathize with the caregiver Understand what you know, what you do not and when to hand off Have comfort with an educational and self-management approach Be aware of personal biases and strong opinions and keep these in check	Communicating purpose of assessment to caregiver Interviewing Engagement, particularly with people who are not asking for help Disseminating information clearly, appropriately and as needed to connect to the care plan

7. How Should Care Recipient and Caregiver Assessments Be Connected?

When separate unique assessment by the same assessor is not possible, ensure information is shared across professionals and settings. If a care plan is done right, it connects the needs and preferences of the care recipient with those of the family caregiver.

—Robyn Golden
 Director of Older Adult Programs
 Rush University Medical Center

Reconciling different needs and desires of the care recipient and the caregiver poses ethical dilemmas regarding whose rights and needs take precedence.

—David Bass, PhD
 Director of Research, Margaret Blenkner Research Institute
 Benjamin Rose

A. Strategies useful in some settings and practices to connect the two assessments include:

- ◆ Incorporating care recipient's needs and preferences into the caregiver assessment
- ◆ Integrating the caregiver in planning and assessment for the care recipient, using a family-centered approach
- ◆ Maintaining flexibility as to who conducts assessment
- ◆ Using technology to enhance accessibility of assessment information and integrating electronic information systems across settings
- ◆ Using the concept of a "care navigator" or "point person" to integrate assessments and respond to care recipient and family needs across settings.

B. Ethical and communication challenges in connecting assessment of the care recipient and assessment of the caregiver need further discussion and more research.

Ethical issues:

- ◆ Potential conflicts between the needs and rights of the care recipient versus the caregiver
- ◆ Confidentiality of sharing and releasing of information for a single point in time and over multiple assessment periods
- ◆ Privacy issues arising from requirements in the Health Insurance Portability and Accountability Act (HIPAA) of 1996
- ◆ Potential conflicts between subjective perspectives of the care recipient and the caregiver
- ◆ Potential conflicts between the care recipient, the caregiver and the service provider
- ◆ Use of one assessor versus multiple assessors for care recipient and caregivers.

Communication issues:

- ◆ Lack of coordination between agencies, and the need to reduce redundancy and fragmentation and increase access to information across settings
- ◆ Determining *how* information from assessments gets shared and *what* information gets shared
- ◆ Using technological solutions to ensure connectivity across settings.

Driving Change: Strategies and Actions

A major shift has occurred over the past decade and family caregiver assessment is now clearly on the policy agenda. But a paradigm shift is needed for policy change—if we are to achieve a focus on recognizing and systematically assessing the needs of caregivers in home and community-based care.

—Susan Reinhard, PhD
Professor and Co-Director
Center for State Health Policy
Rutgers University

Conference participants agreed that policy changes are needed at the federal and state levels to establish systematic caregiver assessment as a basic component of good practice in health care and home and community-based care settings.^v

Conference participants supported this overall policy objective:

- ◆ Consider standardized assessment for all publicly funded programs to alleviate the need for family caregivers to repeat assessments each time they apply for help from a new program.

Three related suggestions were put forth:

- ◆ Include the caregiver's role and service needs in the service plan for a federal or state program if the entitled beneficiary's ability to choose a long-term care option depends upon having the assistance of a family caregiver.
- ◆ Provide reimbursement and reporting for any caregiver assessments that are mandated.
- ◆ Include data collection from caregiver assessments in the current electronic medical record and health information technology initiatives under development within the U.S. Department of Health and Human Services, Office of the National Coordinator (ONC) for Health Information Technology.

^v See Maslow, K., Levine, C., and Reinhard, S. (2005), "Assessment of Family Caregivers: A Public Policy Perspective" in Volume II of this report, *Caregiver Assessment: Voices and Views from the Field*, for a discussion of various public policy options for caregiver assessment.

Conferees set the following priorities for strategies and specific actions to bring us measurably closer to having systematic assessment as part of routine practice (in rank order, top ranked item first):

One to Three Years

- A. Build support for family caregivers among the public, policymakers, government officials, practitioners, insurers, employers and funders:
 - ◆ Add a question on caregiving to the U.S. Census.
 - ◆ Add questions on caregiving to the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System⁸¹ (BRFSS) and state surveys.
 - ◆ Involve professional associations to promote the use of caregiver assessments (e.g., American Geriatrics Society, American College of Physicians, American Psychological Association, National Association of Social Workers).
- B. Conduct demonstration projects to develop and test caregiver assessment practices and protocols as part of the Older Americans Act's National Family Caregiver Support Program (NFCSP).⁸²
- C. Include caregiver assessment by trained assessors in the NFCSP, Alzheimer Disease Demonstration Grants to States⁸³ (ADDGS) and the Aging and Disability Resource Centers⁸⁴ (ADRC). To train assessors, use:
 - ◆ Written materials
 - ◆ Case studies
 - ◆ Videos
- D. Recognize the role of family caregivers in the Medicare Chronic Care Improvement Pilot Program and Demonstration⁸⁵ through performance monitoring and evaluation.
- E. Incorporate caregiver assessment and support needs in Medicaid home and community-based services (HCBS).^{86, 87}
- F. Develop caregiver assessment algorithms (i.e., step-by-step compute problem-solving procedures) to assist decision making. These algorithms should encompass: multiple entry points for caregivers, multiple service providers, links to interventions for caregivers, and different types of assessments.

- G. Add family caregiver assessment as a sixth category of service under the NFCSP and provide a code for reporting it.
- H. Expand dialogue with consumers to discuss caregiver assessment in consumer-directed models of care including discussion on issues related to the developmentally disabled population.

Four to Six Years

- A. Adopt a caregiver policy at CMS to acknowledge the role and contributions of caregivers in the Medicare and Medicaid programs.
 - ◆ Incorporate “quality side” levers. For example, in Medicare hospital discharge planning, caregiver assessment must be made part of a “safe and adequate discharge.”
- B. Develop professional education and training curricula that include caregiver assessment.
 - ◆ Caregiver modules should be developed for physicians, social workers, physical therapists, registered nurses and occupational therapists.
 - ◆ These should be used in continuing education and student training programs.
- C. Advocate for changing record keeping and information systems to include caregiver-related data elements. Focus on:
 - ◆ Large health systems (such as Kaiser Permanente and Department of Veterans Affairs)
 - ◆ Mandated reporting systems (such as the Minimum Data Set)⁸⁸
 - ◆ Smaller electronic record systems.
- D. Support development of a uniform data set and evaluative research to clarify:
 - ◆ Caregivers’ needs and contributions
 - ◆ Resources to meet needs of caregivers
 - ◆ Impact of different assessment approaches.

Conclusion

Caregiver assessment is a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. Because most community-dwelling older people and adults with disabilities rely *solely* on their own families and friends for assistance with daily living and are dependent upon their health and well-being,⁸⁹ establishing caregiver assessment as a core part of the care of persons with chronic or disabling conditions is essential to effective outcomes and quality of care.

Leaders in health care and long-term care have reached consensus about basic principles and guidelines; they agree on the central importance of incorporating an assessment of caregiver needs in everyday practice and service delivery settings. These principles and guidelines arise from available research evidence and expert professional opinion.

Systematic caregiver assessment practices are both desirable and feasible. This consensus report provides credible common ground to focus improvement efforts in both policy and practice and to stimulate applied research geared to successful implementation of well-designed caregiver assessment tools for use in a range of care settings. A consequence of this sharper focus will be increased formal recognition of family caregivers and family-centered care. Consistent approaches to caregiver assessment will help practitioners better understand family needs and capacities; enable family caregivers to access support and remain in their caregiving role as long as appropriate; assure optimal outcomes for the care recipient; and provide solid information to policymakers and program administrators to improve service delivery.

The adoption of these principles and guidelines, embracing a family-centered perspective, will require a fundamental change of thinking in policy and practice. It is hoped that the wide dissemination of this consensus report will encourage the implementation of these caregiver assessment principles and guidelines and the adoption of these recommended change strategies within and across care settings to improve the lives of America's caregiving families.

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⁸¹ The BRFSS is a state-based system of telephone-administered health surveys that generates information about health risk behaviors, clinical prevention practices, and health care access and use related to chronic diseases, injuries, and death. An optional caregiver module is being tested in North Carolina's BRFSS that could be replicated in other states. The caregiver data includes screening questions about caregiving, and follow back interviews of a group of caregivers and care recipients. Also included is a test-retest of the caregiver module on a sample of up to 200 subjects on the North Carolina BRFSS. Results should be available in late 2006.

⁸² The NFCSP was enacted under the Older Americans Act Amendments of 2000 (P.L. 106-501) and is administered by the Administration on Aging (AoA). The program calls for all states, working in partnerships with area agencies on aging and community service providers and tribes, to offer direct services that best meet the range of needs of caregivers of older people (age 60+) including: informa-

tion; assistance; individual counseling, support groups, and caregiver training; respite care; and supplemental services, on a limited basis, to complement the care provided by caregivers. While the NFCSP provides distinct caregiver support services, it includes no mandate for caregiver assessment.

⁸³ The ADDGS Program was established under Section 398 of the Public Health Service Act (P.L. 78-410) as amended by P.L.101-157, and by P.L.105-379, the Health Professions Education Partnerships Act of 1998. The program is administered by the AoA. It is intended to expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families and their caregivers, and to improve the responsiveness of the HCBS system to persons with dementia. A total of 38 states were awarded grants to state agencies in FY 2005.

⁸⁴ The ADRC Grant Program is a cooperative effort of the AoA and CMS. It was developed to assist states in their efforts to create a single, coordinated system of information and access for all persons seeking long-term support. Since 2003, 43 states have received ADRC grants.

⁸⁵ The Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003 (P.L. 108-173, section 721) established a pilot program to test a new model of chronic care improvement for beneficiaries enrolled in fee-for-service Medicare. The new program approach requires contracting organizations to achieve both financial and clinical results, rather than the traditional model of payment for service provided. The program also requires plans to identify beneficiaries with dementia for the purposes of developing a care plan. CMS plans to do a rigorous test of the pilot projects, using randomized controlled trials to evaluate their effectiveness.

⁸⁶ Medicaid, financed by the federal government and the states, is the major public funder for HCBS. The Medicaid HCBS waiver program, authorized by Congress in 1981 and administered by CMS under section 1915(c) of the Social Security Act, is an alternative to providing long-term care in institutional settings. It offers services that Medicaid traditionally does not provide under the regular program, such as respite care or caregiver education and training. To qualify, beneficiaries must meet an institutional level of care and meet state residency and financial requirements.

⁸⁷ Section 6086 of S. 1932, Deficit Reduction Act of 2005, establishes HCBS as an optional Medicaid benefit (without any waiver requirement) for qualified individuals with incomes up to 150% of the federal poverty level. Eligible individuals do not have to be certified as nursing home eligible. Covered services would include those available under the existing waiver program. States that will use this optional benefit must carry out in-person individual assessment that determines service needs, supports an individualized plan of care, and involves consultations with family and relevant health providers. This provision becomes effective on January 1, 2007. (Source: "Summary of the Conference Agreement: Medicare, Medicaid and other Health-Related Provisions," prepared by Health Policy Alternatives, Inc., December 23, 2005).

⁸⁸ The Minimum Data Set (MDS) is part of the federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and identifies health problems.

⁸⁹ Larizgoiti, I. (2003). Approaches to evaluating long-term care systems. In J. Brodsky, J. Habib, and M. Hirschfield (eds.). *Key Policy Issues in Long-Term Care* (222-242). Geneva: World Health Organization.

Appendices

Appendix A:
Conference Participants

Appendix B:
Conference Program

Appendix C:
Process for Developing Consensus

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NATIONAL CONSENSUS DEVELOPMENT CONFERENCE
for CAREGIVER ASSESSMENT:
Translating Research into Policy & Practice

SEPTEMBER 7-9, 2005
CROWNE PLAZA UNION SQUARE
480 SUTTER STREET
SAN FRANCISCO, CA

CONVENER:

National Center on Caregiving
at Family Caregiver Alliance

FUNDER:

The Robert Wood Johnson Foundation
With Additional Support By:
Archstone Foundation
The California Endowment

GOALS:

- Generate principles and guidelines for caregiver assessment
- Build common ground among leaders committed to innovation, experimentation and the systematic generation of new knowledge

AGENDA

SEPTEMBER 7, 2005:

6 – 8 p.m. **Registration and Reception/Light Buffet** — *Russian Hill Room, 30th Floor*

DAY 1 — SEPTEMBER 8, 2005:

7:30 a.m. **Registration and Continental Breakfast**

— *Union Square Reception, Mezzanine Level*

8:30 **Welcome and Conference Overview: The Vision and Consensus Process**
— *Union Square North, Mezzanine Level*

Kathleen Kelly, MPA, Executive Director, Family Caregiver Alliance

Lynn Friss Feinberg, MSW, Deputy Director, FCA's National Center on Caregiving

Laura Peck, MPH, Facilitator, The Claros Group

9:00 **The Voices of Family Caregivers**

Dan Ahern, JD, San Francisco, CA

Carol Levine, MA, New York, NY

9:45 **Break**

10:00 **Highlights of Commissioned Papers: Panel Presentation and Discussion**

Introductions and Overview- *Lynn Friss Feinberg*; Moderator - *Laura Peck*

Research: *Steven Zarit, PhD*, Professor, Department of Human Development and Family Studies, The Pennsylvania State University

Practice: *Nancy Guberman, MSW*, Professor, School of Social Work at the University of Quebec in Montreal

Policy: *Katie Maslow, MSW*, Associate Director, Quality Care Advocacy, Alzheimer's Association

International: *Anne Montgomery, MS*, Health Policy Associate, Alliance for Health Care Reform

11:00 **Break**

11:15 **Draft Principles for Caregiver Assessment**

- Interactive exchange involving all participants in shaping the Principles

12:30 p.m. **Lunch** — *Russian Hill Room, 30th Floor*

- 1:30 **Work Group Deliberations to Develop Guidelines (1):
Defining Issues and Priorities**
All breakout rooms are on the Mezzanine Level
- Group 1: What are the critical domains and outcomes of a caregiver assessment?**
Facilitator: *David Bass, PhD*, Director of Research, Margaret Blenkner Research Institute, Benjamin Rose
Cable Car Room
- Group 2: How should effective caregiver assessments be implemented?**
Facilitator: *Carol Van Steenberg, MS*, Consultant, Family Caregiver Alliance
Sutter I
- Group 3: How do we change practice patterns with respect to caregiver assessment?**
Facilitator: *Robyn Golden, MA, LCSW*, Director of Older Adult Programs, Rush University Medical Center and Chair-Elect, American Society on Aging
Sutter II
- Group 4: What public policies will enable systematic caregiver assessment?**
Facilitator: *Susan Reinhard, PhD, RN*, Professor and Co-Director, Rutgers Center for Health Policy
Sutter III
- 3:15 **Break**
- 3:30 **Work Group Deliberations (2):
Identifying and Refining Options/Seeking Consensus**
Group 1 *Cable Car Room*
Group 2 *Sutter I*
Group 3 *Sutter II*
Group 4 *Sutter III*
- 5:30 **Adjourn formal work for the day**
- 6:45 p.m. **Dinner**
Yank Sing Restaurant
49 Stevenson Place, San Francisco
- DAY 2 — SEPTEMBER 9, 2005:**
- 7:30 a.m. **Continental Breakfast — *Union Square Reception, Mezzanine Level***
- 8:30 **Plenary Challenge Session — *Union Square North, Mezzanine Level***
• Each Work Group solicits feedback from other conference participants
- 10:15 **Break**
- 10:45 **Work Group Deliberations (3):
Drafting Consensus Points and Recommended Guidelines**
Same breakout rooms as Day 1
- 12:15 p.m. **Lunch — *Russian Hill Room, 30th Floor***
- 1:00 **Plenary Consensus Development Session: Bringing It All Together
— *Union Square North, Mezzanine Level***
• Presentation of final draft Principles
• Full group vote on Work Group recommendations
• Prioritization of change strategies
- 3:10 **Wrap Up and Next Steps**
• Recap
• Reflection
• Closing Comments
- 3:30 p.m. **Adjourn**

Process for Developing Consensus

Conference Goals

The goals of the conference drove the process for developing consensus. The goals were:

1. To reach consensus on principles and guidelines for caregiver assessment.
2. To build common ground among leaders committed to innovation, experimentation and the systematic generation of new knowledge.

Deliberation Process

Deliberation took place in both plenary and small group sessions. With a common backdrop, provided through four commissioned papers and presentations, two types of small-group exchange occurred:

- ◆ During the first morning of the conference, participants met in nine discussion groups to deepen their understanding of draft principles and suggest refinements. They were directed, by the Conference Facilitator, to focus on the “big ideas” of each principle for five minutes, identifying points of agreement as well as questions, concerns and recommendations that would strengthen the principle. Each group completed worksheets for each of the six draft principles; most also completed a worksheet with ideas for an additional principle.
 - The Conference Facilitator integrated the nine groups’ suggestions into a second draft, distributed and approved, after a polling process, during a plenary session on the second day.
- ◆ During the first afternoon and the second morning, participants met in four facilitated work groups to give focused attention to specific questions developed by the Advisory Committee. The work groups were designed so each would address an essential component needed to further caregiver assessment in policy and practice: 1) domains and outcomes; 2) structure and implementation; 3) practice patterns, and education and training; and 4) public policy issues.
- ◆ Each work group had two unique questions and three shared questions considered by all groups. (See table on next page for work group ques-

tions.) Participants were pre-assigned to these work groups to assure each included experts in research, policy and practice so divergent experience and perspectives informed deliberations. They addressed their unique questions during two separate sessions and their shared questions during one session only.

Work Group Questions

<i>Work Groups:</i>	<i>Domains & Outcomes</i>	<i>Structure & Implementation</i>	<i>Practice Patterns</i>	<i>Public Policy Issues</i>
Unique Questions	<ol style="list-style-type: none"> 1. What are the most important areas (domains) to assess, and the top 5 questions to ask in each area? 2. Are different domains of assessments needed for the different contexts of settings in which families seek help? 	<ol style="list-style-type: none"> 1. What triggers a caregiver assessment in practice settings? 2. When, where, who and how often should assessments be done? 	<ol style="list-style-type: none"> 1. Are there differences among professionals and care settings in what constitutes a caregiver assessment and the ability to complete a caregiver assessment process? How can these differences be addressed? 2. What training and skills are needed for persons who administer a caregiver assessment? 	<ol style="list-style-type: none"> 1. What health and long-term care policy changes are needed at the federal and state levels to establish systematic caregiver assessment as a basic component of care? 2. How should issues of mandatory requirements, reporting, reimbursement, and information technology be addressed?
Shared Questions	<ol style="list-style-type: none"> 3. How do we connect the assessment of the care recipient and the caregiver? 4. How should assessment findings be used to influence care planning and service intervention? 5. What strategies and specific actions should be taken over the next 1 to 3 years to bring us measurably closer to having systematic assessment as part of routine practice? 4 to 6 years? 			

- ◆ A challenge session, during the second morning, provided feedback to each work group on its two unique questions. The facilitator for each group made a five-minute Power Point presentation of the group's findings on its unique questions. Following each such presentation, the members of the other groups, who were seated together according to their group assignment, discussed the points for ten minutes. As these simultaneous discussions took place, the members of the presenting group, dispersed throughout the room. They observed the discussions of their work and took notes of ideas, questions and concerns raised by other groups' members.
- ◆ Later that morning, the work groups refined recommendations for their unique questions, taking into account the input they had received, and created a second Power Point presentation. The refined presentations were made during a plenary session during the afternoon of the second day. After each presentation, the Conference Facilitator polled the conferees for consensus.
- ◆ For two shared questions (i.e., questions 3 and 4 in the table on page 41), the conference relied on "Integrators" to connect and refine the work generated by each of the four work groups. Four Integrators, representing the Advisory Committee and conference participants, rotated among the groups to observe their work. Each work group facilitator prepared a Power Point summary of its group's response to these two questions. Two of the Integrators had the task of integrating these summaries into a presentation for the second afternoon's plenary session representing the collective work on these questions. After this presentation, the Conference Facilitator polled the conferees for consensus.

Decision-Making Process

The Conference Facilitator provided this direction to conferees: "We will look for common ground around important ideas—not specific language." Participants understood that a white paper, to be written after the conference, would document the consensus opinions and that participants would have an opportunity to review and comment upon this report prior to its general distribution.

When working in discussion and work groups, an informal process was used to test level of agreement. In the final plenary session, two structured processes were employed:

- ◆ For the draft principles and most of the work group recommendations for practice guidelines (the eight unique and two of the shared

questions), the Conference Facilitator called for a poll on how everyone stood on what they had heard:

- After each group report, on the group's two unique questions.
 - After all four reports, on the Integrators' summary of two questions shared by all four groups.
- ◆ For the work groups' recommendations on their third shared question (i.e., question 5 on page 41 on short-term and long-term strategies and specific actions) the Conference Facilitator directed a voting process to identify priorities.
- The four work groups summarized their individual priorities for short and long-term strategies on newsprint sheets and posted these sheets on the wall.
 - Each conference participant was given eight "dots" (four for short-term, four for long-range) to use in voting for the top priorities. They applied these dots to the newsprint; the Conference Facilitator tallied the votes, reported the result and confirmed with the group that the result reflected their strategies and was agreeable to them.

The **definition for consensus** used in this conference was as follows:

Everyone in the group supports, agrees to, or can live with a particular decision. In the end, everyone can say, "I believe you understand my point of view. I believe I understand your point of view. Whether or not I prefer this decision above others, I support it because it was reached fairly and openly." (William Ouchi)

In conducting the polling, the Conference Facilitator's instructions were:

- ◆ If the polling demonstrated complete consensus (100%), the decision was achieved.
- ◆ If the polling indicated 80 percent or more agreement, the individuals not agreeing would be asked, "What will it take to get your adoption?"
- ◆ If the polling indicated less than 80 percent agreement, it would be agreed that this was an area for further discussion and research.

For most items complete (100%) consensus was not achieved. However, after calling for the input of dissenting participants, conferees reached greater than 80 percent agreement without altering the original statement for the principles, practice guidelines and priority of the change strategies adopted at the conference.



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