



**Responding to the Caregiver Crisis:
DRAFT Recommendations for Building
A National Quality Caregiving Network**

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Key Elements of a NQC initiative:

1. Public Health Surveillance
2. Outreach and Education, especially to most in need
3. Multiple, “natural” gateways to service
4. Assessment and “Triage”
5. Stepped Menu of Service Options with Increasing Intensity
6. Professional Development
7. Technical Assistance
8. Accelerated Research and Development
9. Public and Tax Policy
10. Targeted Investments and Sustainable Funding
11. Coordinating Mechanisms

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1. Public Health Surveillance

Recommendation 1a): All states be required to adopt the BRFSS caregiver module to collect data on the characteristics and needs of caregivers in their state and that, whenever possible, surveys be conducted to allow collection of regional and local data.

Recommendation 1b) : A state-level process be developed to use BRFSS Data collected at least every two years to identify critical sub-populations of caregivers most in need and to allocate resources and develop programs in line with identified priorities.

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2. Outreach and Education, especially to most in need:

Recommendation 2: a) A national outreach and public education campaign be developed and funded by DHHS using resources of CMS, CDC, AoA and others to help family caregivers in greatest need recognize, locate and accept assistance and, to inform the public about the needs of family caregivers and how individuals, organizations and faith communities can offer assistance,

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2. Outreach and Education, continued

Recommendation 2b): That effective outreach and education campaigns currently in use or already developed be brought together in a national resource center where communities and agencies can access them for local use,

Recommendation 2c: That evidence-based approaches to outreach and public education to diverse communities regarding caregiving be identified as a priority area for research and development by AoA, CDC, NIH and other federal agencies and that funding be made available to support evaluation of large scale efforts.

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3. Multiple, “natural” gateways to service

Recommendation 3:
That priority be placed on making caregiver support services easily accessible and widely available through naturally occurring gateways including physician's offices, hospitals, faith communities, nursing and home health and rehabilitation organizations, voluntary health organizations, transition care, etc. and other locations and agencies that caregivers are likely to access.

This means that the a priority should be placed on implementation of Evidence-Based Interventions in these sites and in diverse and accessible community locations.

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4. Assessment and “Triage”

Recommendation 4:

That all caregivers be offered the opportunity for a professional assessment of their needs.

Assessments should be culturally competent; should be conducted by someone with the specialized skills to assess caregiver needs and knowledge of caregiver supports; and result in a plan of care outlining services to be provided and measurable outcomes.

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4. Assessment and “Triage”

Recommendation 4, continued:

Recommendation 4b Assessment programs conducted by health care providers (hospital discharge, home care, outpatient, and rehabilitation specialists) or government-funded entities (such as area agencies on aging) have a caregiver component that is available to anyone who identifies themselves as a family caregiver. Caregiver assessments should also be part of home and community-based programs.

Recommendation 4c Government and other third-party payers pay for adequate caregiver assessment as a part of care for older people and children and adults with disabilities.

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5. Stepped Menu of Service Options with Increasing Intensity

Recommendation 5:

Organize the expanded support system around levels of risk: (1) “universal interventions” for all caregivers, (2) “selective interventions” for families at elevated risk for future health and stress-related problems stemming from the demands of caregiving, and (3) “indicated interventions” to further address heterogeneity in risk factors and severity among the high-risk groups. At each level, employ existing EBPs.

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6. Professional Development

Recommendation 6:

That professionals in health care, social work, nursing, occupational and physical therapy, etc. receive intensive training in the needs of family caregivers, how to partner with them, and successful strategies and evidence-based programs to serve them.

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7. Technical Assistance

Recommendation 7:

Technical Assistance networks be established to oversee widespread implementation of EBPs among community agencies. These technical assistance networks could be university- or community-based, tapping into local or national expertise in capacity building, evaluation, and systems design. These resources could provide assistance with guidance from federal or state agencies or from groups like RCI or the VA’s Health Services Research & Development program, which focus on EBPs that could serve as a resource bank or consultant to the consultants. National assistance that is targeted to the particular EBP should also be available and affordable for community agencies.

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8. Accelerated Research and Development

Recommendation 8:

- a) A Medicare multi-site demonstration project be developed utilizing EBP interventions that have undergone clinical trials and been found effective since 1990 when MADDE (the last Medicare Demonstration focused on caregivers) was conducted.
- b) Caregiver intervention demonstration projects should include a cost-effectiveness analysis.

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9. Public and Tax Policy

Recommendation 9:

Design a caregiver credit under the Social Security System as suggested by the General Accountability Office.

Such a credit would either:

- 1) allow a specified amount of caregiving time, perhaps three or four years, to count as covered employment, and assign a wage to that time;
- 2) exclude a limited number of caregiving years from the benefit calculation so that instead of averaging earnings over 35 years, earnings are averaged over fewer years; or
- 3) supplement caregivers' retired worker benefits directly, regardless of whether they took time out of the workforce for caregiving.

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9. Public and Tax Policy, cont.

Recommendation 10:

Create Tax and other incentives for family caregivers to participate in evidence-based programs; tie expanded tax credits to caregiver participation in evidence-based programs.

- b) Governments and other payors provide vouchers for care recipients to pay minimum wage to their informal caregivers.
- c) Tax credits be available for informal caregivers, such as that proposed in the CARE Act by Senator Bob Menendez (D-NJ) in the 110th Congress and considered in several states.

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9. Targeted Investments and Sustainable Funding

Recommendation 11: Invest in a significantly expanded, nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible.

- 11a) Expand Funding for existing federal programs that support caregivers, including the National Family Caregiver Support Program and Alzheimer's Disease Supportive Services Program of the Administration on Aging, and that new funding be made available through Medicare and Medicaid for Caregiver Support Activities.
- 11b) Expand Medicaid home and community-based waiver programs to allow for maximum flexibility to support family caregivers with "wrap-around" services and supports to achieve cost-effectiveness.

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9. Targeted Investments and Sustainable Funding, continued

- 11c) CMS, as an ultimate purchaser of these services, continue to fund successful demonstrations after grant funding ends (three years). Funding could come through a waiver, through the Medicare Advantage program, or other mechanisms. CMS should take on responsibility to further refine these demonstration projects for widespread adoption and institutionalization at a state or national level, and to evaluate cost effectiveness.
- 11d) Quickly implement the "Class Act" which supports development of a new national LTC insurance program. Assure adequate attention to caregiver support, education and training as part of the plan benefits.

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9. Coordination

Recommendation 12:

Create the "NQC National Coordinating Committee" to oversee the entire initiative in the President's or Secretary of DHHS Office. The group should include government and private sector leaders. Specific tasks:

- 1) Develop a clear vision of the caregiver support system to be created and of its various components and underlying principles and its role in the overall Home and Community Based System. Develop a workplan with priority goals and dates for achievement.
- 2) Formalize and define agency-specific roles in the EB Product/Service Development "Pipeline" and create a coordinating body to guide development of EBPs for caregivers from basic research to implementation and sustainability in the community.

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9. Coordination, continued

Recommendation 12: continued.

- 3) Define responsibilities of national, state and local entities in carrying out the initiative.
- 4) Identify all related initiatives and their relevance to the current effort.
- 5) Others

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