



NATIONAL FAMILY CAREGIVERS ASSOCIATION

Family caregivers are noted 15 times in meaningful ways throughout the Patient Protection and Affordable Care Act (Affordable Care Act). They are also mentioned as participants on six advisory boards and commissions. Although given the size of the legislation this is infinitesimal, it is nevertheless significant as recognition of the role family caregivers' play in chronic illness care, and as recognition of the impact this care can have on the health of the caregiver her/himself. The 15 sections that include family caregivers can be grouped together in the following categories:

- *System delivery reform pilot and demonstration projects*
- *Education and training*
- *Long-term care*
- *Quality improvement studies and reports*

I. System Delivery Reform: Pilot and Demonstration Projects

Sec. 3022 Medicare Shared Savings Program

Accountable care organizations (“ACOs”) shall demonstrate to the Secretary that they meet the patient-centeredness criteria, such as the use of patient or **caregiver** assessments or the use of individualized care plans. The Secretary shall determine measures to assess the ACOs quality of care, including patient, and where practicable, **caregiver** experience of care.

Sec. 3024 Independence at Home Demonstration Program

The demonstration program shall test whether a model achieves beneficiary and family **caregiver** satisfaction. It includes education for patient and **family caregiver** about treatment; shared savings program with a minimum 5% savings to Medicare.

Sec. 3026 Community-Based Care Transitions Program

Application to be part of a community-based care transition program for high risk Medicare beneficiaries (and, as appropriate, the primary **caregivers** of the beneficiaries) that: (1) arranges timely post-discharge follow-up services with information regarding responding to symptoms that may indicate additional health problems or a deteriorating condition, (2) provides assistance to ensure productive and timely interactions between patients and post-acute and out-patient providers, and (3) makes assessments through self-management support and relevant information specific to beneficiaries' conditions.

Sec. 3502 Establishing Community Health Teams to Support the Patient-Centered Medical Home

A health team established pursuant to a grant shall (1) incorporate health care providers, patients, **caregivers**, and authorized representatives in program design and oversight, and (2) provide discharge planning and counseling support to providers, **caregivers**, and authorized representatives.

Sec. 3503 Medication Management Services in Treatment of Chronic Disease

The medication management services provided pursuant to a grant shall (1) include collaborative pharmacy practice agreements that include formulating a medication treatment plan according to therapeutic goals agreed upon by the prescriber and the patient or **caregiver** or authorized representative of the patient, and (2) provide education and training designed to enhance the understanding and appropriate use of the medications by the patient, **caregiver**, or authorized representative.

Sec. 3506 Program to Facilitate Shared Decision-Making

The program provides patients, **caregivers** or authorized representatives with information about trade-offs among treatment options, and facilitates the incorporation of patient preferences and values into the medical plan to engage them in informed decision-making with health care providers.

Sec. 3021 Establishment of Center for Medicare and Medicaid Innovation within CMS

The Secretary shall choose several models to be tested with the goal of reducing expenditures and improving quality of services provided. One of the models tested will be the assistance to individuals in making informed health care choices by paying providers of services and suppliers for using patient decision-support tools, which improve applicable individual and **caregiver** understanding of medical treatment options. Additionally, factors considered when selecting models for testing include: (1) whether the model places the applicable individual, including family members and other informal **caregivers**, at the center of the care team of such individual, and (2) whether providers of services and suppliers are able to share information with patients, **caregivers**, and others on a real time basis.

II. Training and Education Opportunities

Sec. 5305 Geriatric Education and Training; Career Awards; Comprehensive Geriatric Education

A geriatric education center that receives an award shall offer at least 2 courses each year to family **caregivers** to provide practical training for supporting frail elders and individuals with disabilities. All family **caregiver** training programs shall include instruction on the management of psychological and behavioral aspects of dementia, communication techniques for working with individuals who have dementia, and the appropriate, safe, and effective use of medications for older adults.

Sec. 5507 Demonstration Projects to Address Health Professions Workforce Needs; Extension of Family-to-Family Health Information Centers

The Secretary shall develop an experimental or control group testing protocol in consultation with a contractor who will evaluate the impact of core training competencies on beneficiary and family **caregiver** satisfaction with services.

III. Long-Term Care

Sec. 2402: Removal of Barriers to Providing Home and Community-Based Services

The Secretary of Health and Human Services shall promulgate regulations to ensure that all States develop service systems that are designed to provide the support and coordination needed for a beneficiary in need of such services (and their family **caregivers** or representative, if applicable) to design an individualized, self-directed, community-supported life.

Sec. 8002 Establishment of National Voluntary Insurance Program for Purchasing Community Living Assistance Services and Support (“CLASS Act”)

The program will alleviate the burdens on family **caregivers**. Additionally, nothing in the Act shall be construed as prohibiting benefits from being paid to compensate a family **caregiver** for

providing community living assistance services and supports to an eligible beneficiary. The Advisory Council shall include family **caregivers** of individuals who require services and supports to maintain their independence at home or in another residential setting of their choice in the community.

Sec. 10202 Incentives for States to Offer Home and Community-Based Services as a Long Term Care Alternative to Nursing Homes

States shall implement conflict-free case management services to develop a service plan, arrange for services and supports, and support the beneficiary (and, if appropriate, the beneficiary's **caregivers**) in directing the provision of services and supports for the beneficiary. States shall collect data, which may include measures of beneficiary and family **caregiver** experience with providers and satisfaction with services.

IV. Quality Improvement Studies and Reports

Sec. 3013 Quality Measure Development

In awarding grants, contracts, or agreements, the Secretary shall give priority to the development of quality measures that allow the assessment of patients, **caregivers**, and authorized representatives to inform decision-making about treatment options, including the use of shared decision-making tools and preference sensitive care.

Sec. 3501 Health Care Delivery System Research; Quality Improvement Technical Assistance

The Center of Quality Improvement and Patient Safety of the Agency for Healthcare Research and Quality shall provide for the funding of the activities of organizations with recognized expertise and excellence in improving the delivery of health care services, by involving multiple disciplines, patients, **caregivers** and families, to share best quality improvement practices and to promote excellence in the delivery of health care services.

Sec. 10331 Public Reporting of Performance Information

The Secretary shall implement a plan for making publicly available through Physician Compare, information on physician performance, which will include an assessment of patient experience and patient, **caregiver**, and family engagement.

The Advisory Boards and Commissions

There are six Advisory Boards created under the Affordable Care Act that call for patient/caregiver/consumer involvement. The Boards will help inform the implementation of the Patient Protection and Affordable Care Act.

Sec. 2801 Medicaid and CHIP Payment and Access Commission (“MACPAC”) Assessment of Policies Affecting all Medicaid Beneficiaries

The membership of MACPAC shall include individuals who have had direct experience as enrollees or parents or **caregivers** of enrollees in Medicaid and CHIP.

Sec. 3403 Independent Payment Advisory Board



The Board makes recommendations to slow the growth of Medicare spending and national health care spending. The President shall appoint 15 members to the board. The council must have members representing **consumers and the elderly**

Sec. 6301 (f) Board of Governors for Patient-Centered Outcomes Research Institute

Carry out the duties of the Patient-Centered Outcomes Research Institute. Board will consist of 17 members appointed by the Comptroller General including three members representing **patients and healthcare consumers**.

Sec. 8002 CLASS Independence Advisory Council

Advise HHS Secretary on administration of CLASS program and in the formulation of regulations under this title including development of benefit plan, determination of premiums, and financial solvency of the program. Council to include among others: **family caregivers** of individuals who require **services and supports**

Sec 8002 (c) Sec 3201) Personal Care Attendants Workforce Advisory Panel

Examine and advise on workforce issues related to personal care attendant works (salaries, benefits, etc). Members shall include: **individuals with disabilities and representatives of individuals with disabilities, seniors, and representatives or seniors**

Sec. 10320 Expansion of the Scope of, and Improvements to, the Independent Medicare Advisory Board

The Medicare Advisory Board shall produce a public report that contains information regarding beneficiary and consumer access to care, patient and **caregiver** experience of care, and the cost-sharing or out-of-pocket burden on patients.