

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

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Health care reform offers new, meaningful supports to assist family and friends in their caregiving role. This Fact Sheet looks at the provisions of the law that specifically address caregivers in health care and in long-term services and supports.

Introduction

Family members, partners, and close friends—often known as “family caregivers”—are the most important source of support to older people and adults with chronic or disabling conditions. They provide the majority of care for loved ones who need help with activities of daily living, such as bathing and dressing, and instrumental activities of daily living, which may include going to medical appointments, taking medications, and paying bills. Family caregivers also increasingly carry out nursing tasks in the home.

The range and complexity of caregiving responsibilities and the stresses associated with arranging, coordinating, and providing care can take an enormous emotional, physical, and financial toll on family caregivers themselves. Their unpaid contributions to family members and friends are the foundation of the nation’s long-term services and supports (LTSS) system and play a key role in health care. Family caregiving also is a significant part of the U.S. economy, with an estimated economic value of about \$450 billion in 2009.¹

The new health care reform law—the Patient Protection and Affordable Care Act

(ACA)²—includes a number of provisions that provide meaningful opportunities to better recognize and address caregiver needs. This Fact Sheet highlights selected ACA provisions that mention family caregivers in important ways.³

First, the law includes individuals and their caregivers as decision makers about care options, and it recognizes the need to address the caregiver’s own experience of care in assessments and quality improvement of services. Second, it promotes new models of care that identify the family caregiver as a key partner. Third, it advances efforts to better prepare family caregivers to perform their care tasks. Last, it enhances opportunities to expand home and community-based services (HCBS) and provide better support to caregiving families. The law explicitly mentions the term “caregiver” 46 times and “family caregiver” 11 times.^{4,5}

Engaging Individuals and Their Families in Shared Decision Making and Addressing Family Experience of Care

Health care and LTSS should be delivered in a way that responds to an individual’s needs, values, preferences, and goals. People with multiple chronic conditions

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

and functional impairments, and especially those with dementia, typically rely on their own family and friends to help coordinate care and to provide essential services and supports. Thus, the perspectives and care experiences of these family caregivers are especially important for quality improvement. According to the National Quality Forum, “Health care should honor each individual [patient] and family, offering voice, control, choice, skills in self-care, and total transparency, and should adapt readily to individual and family circumstances, as well as differing cultures, languages and social backgrounds.”⁶

The ACA calls for developing and implementing a national strategy to improve the quality of health care that includes priorities to assess both the individual’s and the family caregiver’s experience of care. Such new measures and surveys that ask for consumers’ feedback on their care can be important tools to offer direct information to health care providers and health care organizations, and to improve care practices across settings.⁷

The law also establishes opportunities to promote shared decision making. This concept is based on the principle that individuals, their families (if or when desired by the individual), and their health care providers communicate together and have access to timely and understandable information and tools to make shared and informed decisions. Such decisions should respect individual care goals and cultural needs, and help people better manage their health and care options.

The following quality improvement provisions in the law specifically recognize caregivers:

Sec. 3013. Quality Measure Development. The Secretary of the U.S. Department of Health and Human Services (HHS) is required to

develop quality measures that assess the experience, quality, and use of information provided to and used by consumers, caregivers, and authorized representatives. Such information may inform decision making about treatment options, including the use of tools for shared decision making.

Sec. 3403. Independent Payment Advisory Board. This new board will have authority to recommend proposals to slow the growth of Medicare spending. A consumer advisory council will also be established to advise the board. Not later than 2014, and annually thereafter, the 15-member board is required to produce a public report with information on health care costs, access to care, use of services, and quality of care for both Medicare and private payers. Each report is to include, among other information to be detailed, an assessment of consumer and caregiver experience of care.⁸

Sec. 3501. Health Care Delivery System Research; Quality Improvement Technical Assistance. The Agency for Healthcare Research and Quality (AHRQ) is directed to develop and share best practices in improving the delivery of health care services. Such efforts are to involve a range of stakeholders, including consumers, families, and frontline direct care workers. Where applicable, the best practices are to assist health care providers in working with other service providers across the continuum of care and in engaging individuals and their families in improving care and health outcomes.

Sec. 3503. Medication Management Services in Treatment of Chronic Disease. This new program, to be established by the AHRQ,⁹ is to implement pharmacist-provided medication management services that are targeted at individuals with chronic diseases who may be at risk for

medication-related problems to improve the quality of their care. It is to include a medication treatment plan that is agreed upon by the prescriber and the individual or caregiver or authorized representative. It must also provide education and training to the consumer, caregiver, and other authorized representative about appropriate use of medications.

Sec. 3506. Program to Facilitate Shared Decision Making. The Secretary of HHS is required to establish a program that develops, tests, and disseminates certified educational tools, known as “patient decision aids,” to help consumers and caregivers (or authorized representatives) understand and communicate their beliefs and preferences related to their treatment options.¹⁰

Sec. 10331. Public Reporting of Performance Information. Not later than January 1, 2013, the Secretary of HHS must publicly report on the Physician Compare website comparative information on the performance of physicians who participate in the Medicare program. Such information, to the extent practicable, will include an assessment of consumer experience and consumer, caregiver, and family engagement in care.

“Engagement” is generally defined as actions that individuals and their families, as appropriate, must take to get the greatest benefit from the services available to them.¹¹ Such actions may include knowing how to navigate the complex health care and LTSS systems, or managing increasingly sophisticated health technology in the home.

Recognizing Caregivers as Part of the Care Team in New Models of Care

The law promotes new models of care that will better recognize the family caregiver as a key partner in care

and provide more support for family caregivers, especially those who are caring for people with multiple chronic conditions. Starting in 2011, an Innovation Center was established within the Centers for Medicare & Medicaid Services (CMS) to test innovative care and service delivery models—promising new models of payment and service delivery to better coordinate care, improve the quality of services, and lower costs. The provisions in the law that specifically recognize caregivers in new models of care include the following:

Sec. 3021. Establishment of Center for Medicare and Medicaid Innovation. Under the new Innovations Center at CMS, the Secretary of HHS may select models of care to be tested that consider a range of factors, including several components that specifically acknowledge caregivers. These new models—

- Put the individual, including family members and other informal caregivers, at the center of the care team.
- Assist individuals in making informed health care choices by paying providers for using decision-support tools. These tools are to improve individual and caregiver understanding of medical treatment options.
- Share information with individuals, caregivers, and other providers of services in a timely manner.

Sec. 2703. State Option to Provide Health Homes for Individuals with Chronic Conditions. This provision gives state Medicaid agencies a new option to establish health homes (also known as medical homes) for certain Medicaid beneficiaries to promote better coordination and quality of care with a focus on the whole person.¹² In addition to coordinating care with a team

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

of health care professionals and across settings—including linkages to LTSS—designated providers of health homes are required to offer family support, including support services for authorized representatives.

Sec. 3502. Establishing Community Health Teams to Support Medical Homes. A health team established under the medical (or health) home model is an interdisciplinary team-based approach to care, supporting primary care practices in communities, with the individual and caregiver, as appropriate, at the center of the care team. The team must, among other things, incorporate health care providers, consumers, and caregivers (and authorized representatives) in program design and oversight. The team must also provide 24-hour care management and support during transitions in care settings, including discharge planning and counseling support to consumers, caregivers (and authorized representatives), and providers.

Sec. 3022. Medicare Shared Savings Program. A new model of care known as “accountable care organizations” (ACOs) will be established on January 1, 2012, to help health care providers providing services in the traditional Medicare program better coordinate care for Medicare beneficiaries and to offer financial incentives for ACOs that improve quality and certain costs. Under this program, it is envisioned that ACOs will create incentives for health care providers across care settings to work together to improve the health and experience of care for individuals and reduce costs.¹³

ACOs must meet a set of patient-centered criteria, such as the use of individual and caregiver assessments or the use of individualized care plans. The Secretary of HHS will determine measures to assess the ACOs’ quality of care, such as measures of individual and,

where practicable, caregiver experience of care.

Sec. 3024. Independence at Home Demonstration Program. This program will pay physicians, nurse practitioners, and other providers (such as social workers) to deliver primary care services in the homes of high-need Medicare beneficiaries. The three-year demonstration, beginning in January 2012, will test whether the model achieves both consumer and family caregiver satisfaction.

Sec. 3026. Community-Based Care Transitions Program. Beginning in January 2011 and running for five years (with the possibility of expansion beyond 2015), CMS will test models for improving care transitions for high-risk Medicare beneficiaries, including those with multiple chronic conditions, depression, cognitive impairments, or a history of hospital readmissions. The goals of the program are to improve transitions from inpatient hospitals to other care settings, reduce hospital readmissions, reduce costs, and improve quality of care. To test these models, grants will be awarded to eligible community-based organizations (CBOs) that provide a continuum of care, or to acute care hospitals with high 30-day readmission rates that partner with CBOs.¹⁴

Under the law, grantees are required to carry out at least one transitional care intervention, which may include the following:

- Initiating care transition services no later than 24 hours prior to discharge.
- Providing timely post-discharge education to the beneficiary and, as appropriate, the primary caregiver of the beneficiary, regarding symptoms that may indicate additional health problems or a deteriorating condition.

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

- Providing assistance to the beneficiary and, as appropriate, the primary caregiver of the beneficiary, to ensure timely and productive interactions between consumers and post-acute and outpatient providers.
- Assessing and actively engaging with the beneficiary and, as appropriate, the primary caregiver of the beneficiary, to ensure self-management support and relevant information that is specific to the beneficiary's condition.
- Conducting comprehensive medication review and management, including, if appropriate, counseling and self-management support.

Bolstering Education and Training of the Health Care Workforce, Including Family Caregivers

Education and training in geriatric care and chronic care management can improve the services and supports older adults receive and can ease the strain on family and friends, who often feel unprepared for carrying out tasks in the home.¹⁵ The ACA recognizes the need to support family caregivers by providing greater opportunities for training. It also offers opportunities to provide better training to direct care workers (such as home care aides), the largest component of the paid LTSS workforce.

Sec. 5305. Geriatric Education and Training; Career Awards; Comprehensive Geriatric Education. Federally-funded, interdisciplinary geriatric education centers,¹⁶ working with community-based partners, are to publicize and offer in their local service areas at least two courses annually to family caregivers and direct care workers. These courses should provide practical training in caring for frail older adults and individuals with disabilities and include instruction on the management of psychological

and behavioral aspects of dementia, communication techniques for working with persons with dementia, and the appropriate, safe, and effective use of medications for older adults.¹⁷

Sec. 5507. Demonstration Project to Address Health Professions Workforce Needs; Development of Training and Certification Programs for Direct Care Workers. The Personal and Home Care Aide State Training (PHCAST) program is a new three-year state demonstration administered by the Health Resources and Services Administration. It will develop core competencies, pilot training curricula, and establish a certification program for personal or home care aides, projected to be the fourth fastest growing occupation in the United States between 2008 and 2018.¹⁸ On September 27, 2010, the Secretary of HHS awarded grants to six states: California, Iowa, Maine, Massachusetts, Michigan, and North Carolina. These six states estimate that they will train more than 5,100 personal and home care aides by 2013.¹⁹

An evaluation of PHCAST must assess job satisfaction, mastery of job skills, consumer and family caregiver satisfaction with services, and other measures determined by the Secretary of HHS, in consultation with an expert panel.

Sec. 8002. Personal Care Attendants Workforce Advisory Panel. This new advisory body is to examine and advise the Secretary of HHS and Congress on workforce issues related to personal care attendant workers. Membership of the advisory panel is to include individuals with disabilities of all ages, older adults, representatives of older adults, representatives of individuals with disabilities, as well as representatives of service providers, workforce, and labor organizations.

Improving Support for Services at Home and in the Community, and for Family Caregivers

The ACA provides new incentives and programs to strengthen HCBS so that individuals and their family members who want to live in their communities have better options and support services. New provisions²⁰ that specifically recognize family caregivers include financial incentives to states to expand HCBS in the Medicaid program, the establishment of a new voluntary long-term care insurance program, and temporary protections to prevent the impoverishment of community-living spouses of Medicaid beneficiaries who receive HCBS.

Sec. 2401. Community First Choice Option. This new Medicaid state plan option, effective October 2011, provides home and community-based attendant services and supports to certain Medicaid-eligible individuals. States that take up this option will receive a 6 percentage point increase in their federal matching payments for costs associated with the program.^{21,22}

Under this program, attendant services and supports must be based on a person-centered plan that is based on an assessment of functional need. The individual or, as appropriate, the individual's representative (such as the designated family caregiver) must agree with this person-centered plan in writing. Attendant services are selected, managed, and controlled, to the extent possible, by the individual or where appropriate, the individual's representative.

To be eligible, states must establish a Development and Implementation Council, a majority of whose members must be persons with disabilities, older adults, and their representatives. Under the law, the term "individual's representative" is defined as a parent, family member, guardian, advocate, or

other authorized representative of an individual.

Sec. 2402. Removal of Barriers to Providing HCBS. Under Section 2402(a) of the law, HHS must issue regulations to ensure that all states develop service systems that are designed to provide the support and coordination necessary for an individual in need of HCBS—and their family caregiver or representative, if applicable—to design an individualized, self-directed, community-supported life.

Sec. 2404. Protection for Recipients of HCBS Against Spousal Impoverishment. Before receiving Medicaid assistance for nursing home care, home-dwelling spouses of Medicaid recipients in nursing homes can retain a certain amount of income and assets to protect them against impoverishment. The new law requires states to temporarily extend these current spousal impoverishment protections that apply to nursing home care to spouses of Medicaid beneficiaries receiving HCBS. This means that a spouse of a person with disabilities is not required to spend all of the couple's resources to Medicaid eligibility levels so that the spouse with disabilities can qualify for Medicaid HCBS, and the two can remain as a couple at home. This provision becomes effective in 2014 and applies for five years.

Sec. 8002. Establishment of National Voluntary Insurance Program for Purchasing Community Living Assistance Services and Supports (CLASS). The CLASS program is designed to expand options for individuals with functional limitations who require LTSS, and their family members. An explicit intent of this new program is to alleviate burdens on family caregivers.

CLASS has the potential to reduce reliance on Medicaid, help address the

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

financial challenges that families face with the high costs of LTSS, and offer more peace of mind to individuals and their family caregivers. The Secretary of HHS is required to define the CLASS benefit plan by October 1, 2012.²³

Following a five-year vesting period, the program would provide individuals with functional limitations a cash benefit of not less than an average of \$50 per day to purchase non-medical services and supports to help them live in the setting of their choice. The program is financed through automatic voluntary payroll deductions of working adults, unless they choose to opt-out.²⁴ For individuals whose employers do not participate in CLASS, who are self-employed or have more than one employer, the Secretary of HHS would develop an alternative enrollment mechanism to participate in CLASS.

Under the program, the Secretary of HHS will establish procedures to allow access to a participant's cash benefits by an authorized representative of the eligible beneficiary. Authorized representatives, such as family caregivers, must comply with certain standards to ensure that they provide quality services on behalf of the participants, do not have conflicts of interest, and do not misuse benefits paid to the participant.

Family members are permitted to provide services and supports and to receive some compensation for their services. The Secretary of HHS is also directed to establish a Class Independence Advisory Council, which will include family caregivers of individuals who use services and supports to maintain their independence at home or in another residential setting of their choice in the community.

Sec. 10202. State Balancing Incentive Payments Program (BIPP). This program offers financial incentives to states to improve access to HCBS as an alternative to nursing homes.

Participating states are required to make structural changes to their Medicaid program that include three components: (1) a statewide single entry point system, also known as “No Wrong Door” to ensure a consistent experience for individuals seeking information and assistance; (2) a core standardized assessment instrument to determine program eligibility; and (3) conflict-free case management services to eligible individuals. Funding for this new program will be available from October 1, 2011, to September 30, 2015.²⁵

Conflict-free case management services are required 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 Medicaid beneficiary. Participating states must also collect certain information, including measures of beneficiary and family caregiver experience with service providers, as well as their satisfaction with services.

Conclusion

Family caregivers have often gone unrecognized and unacknowledged in the provision of health care and LTSS, despite their essential role as the backbone of the nation's LTSS system. Increasingly, family caregivers are also providing health-related services in the home, but are often unprepared to carry out these complex tasks.

The Affordable Care Act marks an important step forward to better recognize families in their caregiving role and to address their experience of care. These and other provisions in the law have the potential to improve the delivery of health care and LTSS to be more responsive to individual and family needs.

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

Endnotes

¹ L. Feinberg, S. C. Reinhard, A. Houser, and Rita Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*, AARP Public Policy Institute Insight on the Issues 51 (Washington, DC: AARP, June 2011).

² Public Law 111-148, enacted March 23, 2010.

³ Included in this Fact Sheet are references in the Affordable Care Act to *caregiver*, *caregivers*, *informal caregivers*, and *family caregivers*, as well as references to an *authorized representative* or *individual's representative*.

⁴ Other terms in the law that are used in a context that may imply a “family caregiver”—such as “individual’s representatives,” “representatives,” or “authorized representatives”—are noted 13 times in the Affordable Care Act.

⁵ The Elder Justice Act (Sec. 6703) was signed into law as part of health care reform. The program is not yet funded. Its aim is to prevent elder abuse, neglect, or exploitation of older persons by better coordination of efforts across prevention, detection, and law enforcement. Under the act, the term “caregiver” means an individual who has the responsibility for the care of an older adult, either voluntarily, by contract, by payment for care, or as a result of the operation of the law. It includes a family member or other individual who provides paid or unpaid care to an older adult who needs supportive services in any setting.

⁶ National Quality Forum (NQF), *Input to the Secretary of Health and Human Services on Priorities for the 2011 National Quality Strategy*, prepared by the NQF’s National Priorities Partnership (Washington, DC: NQF, October 14, 2010).

⁷ The U.S. Department of Health and Human Services (HHS) released the National Quality Strategy on March 21, 2011. Implementation efforts are under way. U.S. Department of Health and Human Services, *The National Strategy for Quality Improvement in Health Care: Report to Congress* (Washington, DC: HHS, March 2011).

⁸ The Kaiser Family Foundation, *Explaining Health Care Reform: Medicare and the New Independent Payment Advisory Board* (Washington, DC: The Henry J. Kaiser Family Foundation, May 2010).

⁹ This program is not yet funded.

¹⁰ Section 3506 of the Affordable Care Act defines “preference sensitive care” as the situation when evidence does not support one specific treatment option, but rather the decision on treatment depends on the values or preferences of the individual and caregivers (or authorized representatives) regarding the benefits, harms, and evidence for each option. Use of such care should depend upon the individual’s informed choice of a clinically appropriate treatment option.

¹¹ Center for Advancing Health, *A New Definition of Patient Engagement: What Is Engagement and Why Is It Important* (Washington, DC: Center for Advancing Health, 2010).

¹² L. Flowers and W. Fox-Grage, *Health Reform Law Creates New Opportunities for States to Save Medicaid Dollars*, AARP Public Policy Institute Insight on the Issues 52 (Washington, DC: AARP, July 2011).

¹³ U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Improving Quality of Care for Medicare Patients: Accountable Care Organizations*, https://www.cms.gov/MLNProducts/downloads/ACO_Quality_Factsheet_ICN906104.pdf.

¹⁴ U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services, https://www.cms.gov/DemoProjectsEvalRpts/downloads/CCTP_Solicitation.pdf.

¹⁵ Institute of Medicine, *Retooling for an Aging America* (Washington, DC: The National Academies Press, 2008).

¹⁶ On August 5, 2010, the Health Resources and Services Administration awarded \$17.2 million in geriatric education center awards to 45 academic institutions to improve training of health professionals in geriatrics; develop curricula relating to treating health problems of older people; and support continuing education for health professionals in geriatric care, <http://www.hhs.gov/news/press/2010pres/08/20100805a.html>, accessed August 26, 2011.

¹⁷ This training program does not include specific funding.

Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers

¹⁸ Paraprofessional Healthcare Institute, *Facts 1: Occupational Projections for Direct-Care Workers 2008-2018* (New York: Paraprofessional Healthcare Institute, February 2010), http://directcareclearinghouse.org/download/PHI%20FactSheet1Update_singles%20%282%29.pdf, accessed August 26, 2011.

¹⁹ U.S. Department of Health and Human Services, HHS Awards \$159.1 Million to Support Health Care Workforce Training [Press Release], <http://www.hhs.gov/news/press/2010pres/09/20100927e.html>, accessed August 26, 2011.

²⁰ Another new provision, Sec. 2801 of the Affordable Care Act, funds and expands the role of the Medicaid and State Children's Health Insurance Program (CHIP) Payment and Access Commission (MACPAC) to include assessments of adult services in Medicaid. Membership of MACPAC must include representation of individuals who have direct experience as beneficiaries or parents or caregivers in Medicaid or CHIP (including older adults, individuals with disabilities, caregivers, and dual-eligible individuals), as well as experts in the field.

²¹ L. Walker, *Health Care Reform Improves Access to Medicaid Home and Community-Based Services*, AARP Public Policy Institute Fact Sheet 192 (Washington, DC: AARP, June 2010).

²² Flowers and Fox-Grage, *Health Reform Law Creates New Opportunities for States to Save Medicaid Dollars*.

²³ R. Richards and L. Walker, *Understanding the New Community Living Assistance Services and Supports (CLASS) Program*, AARP Public Policy Institute Fact Sheet 183R (Washington, DC: AARP, February 2011).

²⁴ The Kaiser Family Foundation, *Summary of New Health Reform Law*, Publication #8601 (Washington, DC: The Henry J. Kaiser Family Foundation, April 15, 2011).

²⁵ Walker, *Health Care Reform Improves Access to Medicaid Home and Community-Based Services*.

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