This paper describes the Centers for Medicare and Medicaid Services' (CMS)' legal authority to support caregivers and the ways in which CMS currently supports caregivers through its programs. It is intended to serve as a resource for organizations that work on behalf of caregivers.

Caregivers are broadly defined as family members, friends, or neighbors who provide unpaid assistance to a person with a chronic illness or disabling condition. The nature of the assistance could include helping the person with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs); performing "medical" tasks such as administering intravenous drugs or caring for wounds; acting as the person's legal representative; or other activities. In 2003, there were an estimated 44 million adult caregivers in the U.S.[1]

CMS' Legal Authority to Support Caregivers

This section describes CMS' legal authority to support caregivers and The Health Insurance Portability and Accountability Act (HIPAA) rules pertaining to the disclosure of information to caregivers.

Medicare Part B- and Medicaid-covered Visits from Physicians and Qualified Non-Physician Practitioners: Physicians and qualified non-physician practitioners must submit Medicare and Medicaid claims using HIPAA-compliant codes such as CPT codes. The CPT codes for office (99201-99215), home (99341-99350), and domiciliary (99324-99337) visits include counseling and/or coordination of care with other health care providers. This includes time spent with family members and other caregivers who have assumed responsibility to care for the patient or assist with their decision-making. Family members or other untrained, nonprofessional caregivers can be educated and/or trained during a service where the health care provider is evaluating and treating the patient for a covered and medically necessary service. However, the visit cannot be performed for the sole purpose of such training.

In Medicaid, States have flexibility to pay for caregiver services separately. Providers may use HCPCS code T1027, "Family training and counseling for child development, per 15 minutes" to bill for services provided to caregivers, if this is allowed by the State.

Medicare-and Medicaid-covered Hospice: The hospice benefit is designed to enable the beneficiary to remain in the home and to support the family. Hospice services include medical care, nursing care, homemaker services, home health aides, medications, durable medical equipment, social services and other services as needed. Caregiver training is provided so that the caregiver will be able to better support the beneficiary. The

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[1] Caregiving in the United States, National Alliance for Caregiving and AARP, April 2004. The study was based on a national survey of 6,139 adults in the U.S. Caregivers were defined as people age 18 years or older living in the U.S. who provide assistance with one or more ADLs or IADLs to someone 18 years of age or older.

beneficiary may be placed in an inpatient facility for up to five consecutive days to provide respite for the caregiver. Family grief counseling is available for up to a year after the beneficiary's death.

Medicaid Waivers: Under 1915(c) waivers, States may provide respite care, training and family counseling. They may also pay legally responsible relatives to provide care that is "extraordinary" (example: a parent lifting a 1-year-old is ordinary; lifting a 16-year-old is extraordinary). The services provided by the caregiver need to be necessary in order to prevent the beneficiary from being institutionalized. In addition, the relatives or friends must meet the qualifications for providers of care, and other criteria must be met.

Medicaid State Plan Option for Home and Community-Based Services:
Section 1915(i) of the Deficit Reduction Act (DRA) of 2005 enables States to provide home and community-based services as a State plan option. Under this option, States may provide some of the same services to caregivers that are available under 1915(c) waivers (see above).

Medicaid State Plan Option for Self-directed Personal Assistance Services: Section 1915(j) of the DRA enables States to offer a self-directed service delivery model for personal assistance services (i.e., cash and counseling programs) as a State plan option. These programs enable beneficiaries to pay legally liable relatives (parent, spouses, and others) directly for personal assistance services identified in the service plan and budget.

Medicare-covered Home Health Agency (HHA) Services: Section 1861(m) of the Social Security Act (SSA) defines Medicare home health services as skilled nursing care, certain therapies (e.g., physical therapy), medical social services, home health aide services, and medical supplies and DME. Skilled nursing care and medical social services can include caregiver supportive services. For example, teaching and training activities that require skilled nursing personnel to teach a patient or a beneficiary's caregivers on how to manage his/her treatment regimen can be considered a skilled nursing service covered under the home health benefit. Medical social services can include assessing the relationship of the patient's medical and nursing requirements to the patient's home situation; the beneficiary's financial resources and the availability of community resources; or action needed to obtain available community resources or to assist in resolving his/her issues.

Medicare Durable Medical Equipment: DME suppliers are required to train the beneficiary and/or their caregivers how to manage the beneficiary's equipment.

Medicare Advantage (MA) Plans: The Medicare Managed Care Manual allows MA plans to offer electronic monitoring of beneficiaries as a supplemental benefit (Chapter 4, Section 20.16). Additionally, in certain specific circumstances, an MA plan may offer respite care as a supplemental benefit (e.g., for a limited time period such as during a transition) (Chapter 4, Sections 10.10 and 20.24). In addition, plans may offer, as an administrative service, assistance to caregivers in identifying community-based resources specific to the needs of the beneficiary.

HIPAA rules pertaining to the disclosure of information to caregivers: The HIPAA Privacy Rule, at 45 CFR 164.510(b), permits a health plan (or other covered entity) to disclose protected health information (PHI) to a family member, relative, close personal friend, or any other person identified by the individual when the PHI is directly relevant to the person's involvement with the individual's care or payment for the care.

A covered entity may only disclose this PHI to these persons if the individual is present and does not object to the disclosure or the covered entity can reasonably infer from the circumstances that the individual does not object to the disclosure. If the individual is not present or is incapacitated, the covered entity can make the disclosure if, in the exercise of professional judgment, it believes the disclosure is in the best interests of the individual.

CMS Support for Caregivers

This section describes CMS' current activities to support caregivers in the areas of information, respite care, assessment, training, direct payments to caregivers and research.

Information

Aging and Disability Resource Centers (ADRCs): The ADRC grant program is a cooperative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS). This program 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, and to minimize confusion, enhance individual choice, and support informed decision-making. ADRCs provide information and access to long-term supports to persons with disabilities of all ages and older Americans, regardless of payer status, and their caregivers. Implementation grants have been awarded in 43 States and territories. As of October 2006, there were over 100 ADRCs. Twenty percent (20%) of the total U.S. population has access to an ADRC.

Publications: The CMS Office of External Affairs (OEA) has developed two publications for caregivers that are disseminated through several groups convened by CMS as well as other partner organizations. The first publication, *Medicare Basics: A Guide for Families and Friends of People with Medicare*, defines eight "decision points" related to the health or overall well-being of an older person and, for each of those points, provides basic information about Medicare and suggestions on finding more detailed information via non-profit organizations. The second publication, *When Employees Become Caregivers: A Manager's Workbook*, guides employers in how to make information on eldercare and Medicare available to caregiving employees at little or no cost.

Workgroups: The Office of External Affairs (OEA) convenes several groups with an interest in disseminating information to caregivers. The CMS Caregiver Workgroup, which meets quarterly, includes a cross-section of organizations such as caregiver organizations, aging network organizations, Federal Agencies, disease-specific organizations, employers, and others. The CMS Employer Forum has a monthly conference call and is composed of major business associations representing over 10,000 employers and over 78 million employees. Finally, the CMS Union Forum has a monthly conference call and includes 65 major unions, which represent 13 million union members including employed caregivers and retirees.

Conference Calls: CMS sponsors quarterly conference calls in conjunction with the National Alliance for Caregiving to disseminate information to caregiver coalitions. The coalitions are local groups which bring together a cross-section of organizations and individuals with an interest in helping family caregivers obtain services and information.

Family-to-Family Health Care Information and Education Centers: CMS and the Health Resources and Services Administration (HRSA) have awarded 36 grants worth $7 million since 2002 for States to establish Family-to-Family Health Care Information and Education Centers. These centers provide information to families of children with special health care needs to help them navigate the health care system and make informed health care choices for their children. One aspect of the model is that families give information to and mentor other families. Ten of CMS' grants have been extended through September 2007.

Respite Care

Medicaid Waiver Programs: The Medicaid program permits States to offer respite to caregivers through the Home and Community-Based Waiver Program (section 1915(c) of the Social Security Act). A 50-state study on caregiving published by the Family Caregiver Alliance in November 2004[2] found that 44 out of 49 states with Medicaid waivers covered respite care for caregivers of frail elders or persons with disabilities. In the year studied, section 1915(c) waiver programs paid $84.5 million for respite care.

Program of All-Inclusive Care for the Elderly (PACE): PACE is a Federal-State program for the frail elderly that provides comprehensive services. It may be available in States that have chosen it as an optional Medicaid benefit. PACE participants are 55 years of age or older, determined by the State to need nursing home level of care, and reside in the PACE programs' service area. The PACE program utilizes an interdisciplinary team that develops a plan of care with the participant that include services in various settings including the home. A PACE program can incorporate

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[2] The State of the States in Family Caregiver Support, Family Caregiver Alliance, November 2004.

caregiver services into the care plan and make respite services available to caregivers. As of 2007, there are 37 PACE programs that serve approximately 13,000 enrollees.

Medicare Demonstrations: In 2006, CMS launched the Medical Adult Day Care Services Demonstration, a three-year Medicare demonstration that encourages Home Health Agencies (HHAs) to partner with Medical Adult Day Care Facilities (MADCFs) to provide medical adult day-care services to Medicare beneficiaries as a substitute for a portion of home health services otherwise provided in the home. The demonstration will provide caregivers with respite while their loved ones attend adult day care.

Medicaid Demonstrations: In the Money Follows the Person (MFP) Demonstration, CMS has awarded five-year grants to 30 States and the District of Columbia to transition eligible individuals from institutions into the community. The grants will pay for one year of community-based services for each person transitioned, which may include respite programs for caregivers. In the Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration, CMS has awarded five-year grants to 10 States to transition children from psychiatric residential treatment facilities into the community. States may also use the grant money from this demonstration to offer respite programs for caregivers.

Assessment

Medicaid Waiver Programs: The Family Caregiver Alliance's 50-State survey (referenced above) found that about half of the 150 State programs surveyed assessed caregiver needs in some way. Twenty-two percent (22%) of the programs that included assessment were Medicaid Waiver programs.

Medicaid Real Choice Systems Change Grants: In September 2007, CMS will award over $13 million in Real Choice Systems Change Grants. Approximately $8.9 million will be awarded to States to plan and implement person-centered planning (PCP) models. CMS defines PCP models as those that enable the individual to direct his or her care assessment and planning process. These models support incorporation of variables other than medical need into the care assessment and planning process. CMS required grantees to incorporate a systematic assessment of caregiver needs and caregiver support into the PCP models that will be developed under these grants.

Outcome and Assessment Information Set (OASIS): OASIS data is collected on most adult Medicare and Medicaid beneficiaries who are receiving skilled health services from a home health agency (HHA). OASIS asks several questions about caregivers to ascertain the extent of caregiver availability.

Continuity Assessment Record and Evaluation (CARE) Instrument: CMS is developing the CARE instrument for use in the Post-Acute Care Payment Reform Demonstration mandated by Section 5008 of the Deficit Reduction Act (DRA) of 2005.

The assessment instrument will be used at hospital discharge and periodically throughout the ensuing episode of care and will include questions related to caregivers.

Training

Health Care Providers: As described in the previous section, the Medicare and Medicaid payment systems offer latitude for physicians and other practitioners to provide training to caregivers in the contexts of home health and office visits.

Medicaid Waivers: Under 1915(c) waivers, States may provide training to caregivers to the extent it is necessary to enable the participant to be cared for outside of an institution. Training includes instruction about treatment regimens and other services included in the service plan, use of equipment specified in the service plan, and includes updates as necessary to safely maintain the participant at home. All training for individuals who provide unpaid support to the participant must be included in the participant's service plan.

Aging and Disability Resource Centers (ADRCs): Aging and Disability Resources Centers (ADRCs) provide referral to training programs.

Direct payments to caregivers

Medicaid Self-Direction Programs: Under the self-directed care service delivery model, Medicaid beneficiaries, instead of an agency, hire, supervise, manage and train the workers who furnish their personal care and related services. Most beneficiaries hire family members, friends or other persons known to them to provide their care.

Two national pilot projects demonstrated the success of the self-directed service delivery model. During the mid-1990s, the Robert Wood Johnson Foundation awarded grants to develop self-determination programs in 19 States. These projects primarily evolved into Medicaid-funded programs under the section 1915(c) home and community-based services waiver authority. In the late 1990s, the Robert Wood Johnson Foundation again awarded grants to develop the "Cash and Counseling" national demonstration and evaluation project in three States. These projects evolved into demonstration programs under the section 1115 demonstration authority. Since the pilots were conducted, many additional States have implemented self-direction programs, including Independence Plus programs, under waiver or demonstration authority.

On February 8, 2006, the Deficit Reduction Act (DRA) of 2005 was enacted into law (Pub. L. 109-171). Section 6087 of the DRA amended section 1915 of the Social Security Act (the Act) to add new subsection (j). Section 1915(j) allows a State to furnish self-directed personal assistance services as a State Plan option. Section 6086 of the DRA amended section 1915 of the Act to add new subsection (i). Section 1915(i) allows States to provide home and community based services, as defined in Section 1915(c)(4)(b) of the Act, under their Medicaid State Plans. States may elect to offer individuals receiving services through 1915(i) the option to direct some or all of their services under that authority.

As of August, 2007, CMS estimates that 43 States offer 111 self-direction programs under a variety of Medicaid authorities, including section 1915(c) waivers, section 1115 demonstrations, concurrent section 1915(b)/(c) waivers, the State plan personal care option and the new DRA State plan options to offer self-directed services.

Research

Medicare Current Beneficiary Survey (MCBS): The MCBS is a national, longitudinal survey of Medicare beneficiaries that has been conducted every year since 1991. Separate questionnaires are administered to participants who live in the community and those who live in institutions. The community questionnaire collects some information on who helps the survey participants to perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).