Policy Clarification for Caregiver Services and Respite Options for Families of Older Adults

TOPIC
Clarification of policy for caregiver education and training, respite care services, consumer directed respite options, companion and adult day services under EW and AC. This replaces bulletin #03-25-06.

PURPOSE
Improve access to caregiver services and other respite options for family caregivers of person 60 years and older.

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BACKGROUND

Supporting family caregivers is a major strategy for extending Minnesota’s publicly funded long-term care system. The care provided by families and others in Minnesota alone is valued at $5.35 billion per year\(^1\). Family or informal caregivers are defined as spouses, relatives, partners, friends or neighbors, who have a significant relationship with and provide a broad range of unpaid assistance for an older adult or other individual. Shorter hospital stays and limited discharge planning necessitate that families and friends provide more difficult, intense care for longer periods of time. Family caregivers provide an estimated 92% of the care needed by older adults. However, this care is declining due to smaller family size and high female workforce participation coupled with increasing numbers and longevity of older adults. Caregiving can take a physical, mental, emotional and financial toll on families and friends. Family caregivers have significantly higher depression and mortality rates than non-caregivers. In addition, the majority are employed full-time or part-time (59%) and must balance the multiple demands of work, caregiving and family. These caregivers make work-related adjustments often resulting in lost wages (and some giving up work entirely). Their well being is intricately linked to the well being of those they care for.

The Department of Human Services and the Minnesota Board on Aging (MBA) recognize the critical role of family caregivers and the importance of a statewide system of supports to prevent further declines in caregiving resulting in increased use of more costly forms of care. The vision of this system is that *Minnesota caregivers will get the support they need to provide care for older adults and others*. The goal is to develop a comprehensive coordinated system of services and supports that is person-centered, affordable, accessible and diverse to meet the needs of caregivers. The system outcome is to support family caregivers to improve the quality and duration of care provided and to reduce reliance on more costly forms of long-term care. Development of this statewide system includes:

- Assuring broader access to caregiver supports across programs and funding streams [e.g. Title III-E Older Americans Act, Elderly Waiver (EW), Alternative Care (AC), state funded grants\(^2\) and private insurance].
- Expanding the range and intensity of caregiver supports available in communities.
- Raising public awareness of caregiving, including working and long distance caregivers and their employers, and increasing acceptance of caregiver supports.
- Implementing a quality assurance component including evidence-based practices and models of support.

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2 Includes state Respite and Community Service/Service Development Grants
Locally, the development of Minnesota’s family caregiver support system continues to grow through collaborative efforts among lead agencies, Area Agencies on Aging (AAAs), Eldercare Development Partners (EDPs), providers, block nurses, parish nurses, faith-based and voluntary organizations, universities and colleges, businesses and employers, physicians and clinics, consumers, tribal agencies and others.

Lead agencies (e.g., counties, managed care organizations and tribes) play a key role in assuring access to caregiver supports, and are important partners in local planning and design, early identification and referral, and assuring quality of services and supports. Managed care organizations or entities have the opportunity to market family caregiver support services as an added benefit (or incentive) for plan members and their families.

INTRODUCTION

This bulletin clarifies policy, standards and payment related to publicly-funded services for supporting Minnesota’s family caregivers:

- Caregiver services including caregiver education and training (including counseling and coaching) and respite care services.
- Formal services with a respite outcome such as companion services and adult day services.

FAMILY CAREGIVER SERVICES

Strategies for supporting family caregivers are the most effective when based on identified needs, preferences and the stage of caregiving. The Caregiver Identity Theory\(^3\) is based on the premise that caregiving is a dynamic change process that involves changes in care activities, relationships and changes in the caregiver’s identity. Caregiver stress can be reduced by identifying the stage of caregiving and matching goals and support strategies with appropriate services and supports. This strategy can maximize the impact of support services and target limited resources more effectively.

Multi-component service interventions have been shown to be most effective in reducing caregiver stress and depression, and increasing caregiver well being. These interventions should be offered early in the caregiver career and be customized to address the individual needs of the caregiver and stage of caregiving. Examples of multi-component caregiver support interventions include:

- caregiver counseling/coach + respite care + support groups
- caregiver education/training (skills-based) + consumer directed respite + home modifications and technology supports

\(^3\) Montgomery, R., Kosloski, K., Pathways to a caregiver identity for older adults. Talley & R.J.V. Montgomery (Eds.), *Caregiving across the life span*. New York: Oxford University Press. 2001
A recent study\(^4\) found that multi-component caregiver interventions for families caring for someone with Alzheimer’s disease delayed nursing home placement by 1-1/2 years and improved caregiver well-being (e.g., increased ability to manage care recipient’s behavior, improved satisfaction and fewer symptoms of depression).

The EW and AC programs include caregiver services for family caregivers of eligible older adults. Caregiver services are incorporated into the community support plan and paid for through the care recipient’s monthly service cap. The care coordinator or case manager monitors the changes in caregiver’s needs, status and adjusts the plan, as appropriate. National Family Caregiver Support Program funding, Title III-E of the federal Older Americans Act, is used to develop and subsidize caregiver services for persons who are not eligible for payment under EW or AC, or when the care recipient’s monthly service cap is maximized. Title III-E services exist under contract with Minnesota’s Area Agencies on Aging (AAAs) and depend on availability of funding. In addition, Living At Home/Block Nurse Programs (LAH/BNPs), parish or congregational nurse programs, faith-based organizations, and others may also provide caregiver support services. To locate caregiver support services call the Senior LinkAge Line\(^®\) at 1-800-333-2433 or online at [www.MinnesotaHelp.info](http://www.MinnesotaHelp.info).

### 1. CAREGIVER ASSESSMENT

Caregiver screening and assessment are critical first steps in supporting caregivers. Early identification and referral can help reduce caregiver stress and burnout, linking caregivers with appropriate resources and supports. The assessment focuses on the caregiver as the primary customer. It is a systematic process of gathering information that describes a caregiving situation and particular needs, resources and strengths of the family caregiver(s). It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need and the outcomes they desire for support, and to maintain their own health and well-being\(^5\).

The DHS encourages lead agencies to use the caregiver assessment questionnaire (DHS 3428-ENG – Section P.) during the long-term care assessment and re-assessment processes, or an evidence-based, person-centered tool to screen and refer caregivers for resources and supports under EW and AC. Examples of referrals include caregiver training and education, caregiver counseling or coaching, and respite care services including in-home, out-of-home or consumer-directed options. See Chapter 26A of the Minnesota Health Care Programs (MHCP) provider manual for standards, qualifications and billing codes [MHCP Provider Manual](http://MHCPProviderManual).

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II. FAMILY AND CAREGIVER TRAINING AND EDUCATION

Family and caregiver training and education services available under EW and AC include individual or group advice, consultation, or information to help the caregiver provide unpaid care to another individual. Training and education can be provided in-person in the home, outside of the home, or on-line via the internet depending on the needs of the caregiver. Education and training programs should be matched with the caregiver’s identified needs and goals:

- **Information-based programs** about a disease or services and supports related to providing the care. Includes education about a disease, a disease process, consumer and home safety, assistive technology, home modifications, home and community-based services, end-of-life care and decision making, legal and financial information.

- **Skills-based programs** to help the caregiver acquire knowledge and skills needed to provide the care. Includes education on direct care skills (i.e., bathing, dressing and transferring), treatment regimens, disease and medication management, communicating with health care providers, building an informal network of support (i.e., family, friends and neighbors).

- **Psycho-educational programs** to help the caregiver build a sense of mastery, confidence and coping skills needed to provide the care. Includes understanding and managing difficult behaviors, caregiver role development and identity change, family dynamics, communications skills, cognitive reframing, coping skills, self-care skills and understanding grief and loss.

A variety of caregiver education curriculums is available. Some examples include *As Families Grow Older*, a standardized curriculum, is available statewide through the regional AAA networks, *Savvy Caregiver* and others. The *Savvy Caregiver* is an evidence-based training for families caring for persons with Alzheimer’s disease and may be available through your local Alzheimer’s Association Regional Centers.

Support groups with an educational component are also included as a caregiver education and training service under EW and AC. These support groups allow for sharing and normalization of the caregiving experience, provide encouragement and validation of efforts, and contain an educational component.

Caregiver counseling is an individualized service directed to the needs of the caregiver as they relate to providing care to the recipient. The primary purpose of this service is to help the caregiver become better prepared and equipped to provide the necessary care to the recipient. Service components may include care and disease management, guidance or instruction on various topics related to the care (e.g., communication with health care professionals, advocacy, personal well-being), or other topics as authorized in the individual support plan.
A “caregiver coach” is also an individualized service under caregiver education and training. A coach can assist a caregiver in identifying needs/values, goal setting and developing a self-directed action plan. A caregiver coach provides ongoing validation and support. Under EW and AC, a caregiver coach has a degree in social work, nursing, gerontology, other related field and at least one year of experience working with caregivers and older adults. The family caregiver is the primary client of the coach. Caregiver coaches have specialized training in chronic disease management, conducting family meetings, teaching self-advocacy and navigating the health and long-term care system. Coaches follow established standards and are trained to a specific curriculum developed under Title III-E of the National Family Caregiver Support Program.

Family caregiver training and education services may be used by family caregivers who provide direct and ongoing care to EW and AC recipients. Lead agencies are encouraged to contract with providers of caregiver education and training ([Billing code is S5116 for EW and AC recipients for each session](#)). Caregiver education and training or support groups may be available in communities free of charge, for a sliding fee scale fee or donation. Employees or volunteers of provider organizations and licensed foster care providers are not considered family or informal caregivers and, therefore, are not eligible to receive caregiver education and training, respite and counseling services paid under public funds (e.g., EW, AC, Title III, state grants).

Providers of caregiver education and training services include some respite providers, non-profit social service agencies, parish or congregational nurse, LAH/BNPs, community or technical colleges, and chronic disease organizations, such as the Alzheimer’s Association, the Minnesota Stroke Association, the Struthers Parkinson’s Center, and others. Contact your local AAA through the Senior LinkAge Line® at 1-800-333-2433 or log onto [www.MinnesotaHelp.info®](#) to learn about resources in your area.

**III. RESPITE CARE SERVICES – EW and AC POLICY**

The primary purpose of respite care services is to provide relief from caregiving responsibilities for unpaid family or informal caregivers. Respite care services may include individualized supervision, or personal care or nursing care provided in the short-term absence of the primary informal caregiver. Services may be provided by licensed or paraprofessional staff, volunteers, or informal adult providers (e.g., friends, family or neighbors) with the skills and ability to provide the service.

*The goal is to have family caregivers get the respite they need, when, where, and from whom they choose.* New respite options are needed to address the diverse needs of caregivers, including different types and levels of care needed.
Here are some considerations for respite care services:

- Respite has the most impact on family caregivers when used *early and often (two to three times per week)*.

- A well developed respite package should contain a variety of respite options (e.g., overnight, in-home, adult day services, etc.) that allow the caregiver to maintain their well-being and lifestyle while providing care.

- Respite services are provided at the level of care and supervision necessary to ensure the health and safety of the care recipient.

- Respite can be provided while the caregiver is away or at home with the recipient. Family caregivers do not have to be living with the recipient in order to receive respite. For in-home respite, services may be provided in the recipient's or family caregiver's residence.

- Respite care services are not available for the paid hours of care provided by family and informal caregivers, such as personal care assistants (PCA) under the PCA Choice program, consumer-directed community supports, or via a relative hardship waiver (AC program only). However, respite services may be authorized for the unpaid hours of care provided by these family or informal caregivers under EW and AC.

- Case managers and aging network providers need to plan for cost-effective respite services that match the needs of the recipient with the appropriate provider type. *For example, a person with early Alzheimer's disease receiving assistance from a caregiver with meals, supervision, and companionship does not necessarily need respite services from a licensed home care agency. A trained respite volunteer from a faith-based agency, church, or neighbor should also be considered.*

**Billing EW/AC for Respite Care Services**

For EW and AC coverage, respite care services must be provided in an approved site by an approved provider under a lead agency contract. Respite services and payment rate limits in EW and AC programs were developed for care recipients who typically need hands-on care (e.g., personal cares or nursing). However, respite services are increasingly needed for caregivers of persons with supervision and monitoring needs due to an illness or dementia-related condition. Therefore, the complexity of the person’s need and the skill required to provide the care should be reflected in the negotiated payment rate and the qualifications of the provider.

Only services that are established for purposes of respite for a family caregiver may be billed as such. Services cannot be billed under the respite codes if the recipient does not
have a family or informal caregiver. EW and AC respite billing codes should not be used when the service is established for meeting the on-going needs of the recipient. Other services (e.g., adult day care, companion) are designed to address these needs.

Under EW, respite care services are not available to family caregivers of persons receiving customized living, 24 hour customized living, adult foster care, or residential care services. In these situations, the customized living, residential, or adult foster care provider is a paid caregiver.

Adult foster care providers may have contracts to provide respite care in these settings but cannot bill for adult foster care and respite for the same person on the same days.

In-home respite is billed to EW and AC under one of these codes: S5150 (15-minute unit) or S5151 (daily rate). Out-of-home respite is billed to EW and AC under one of these codes: S5150 with modifier UB (15-minute unit) or H0045 (daily rate) that includes hospital, adult foster care, customized living and nursing home settings providing 24-hour overnight service. In general, daily rates were developed for overnight stays and include room and board costs. However, lead agencies may use daily rates for services less than 24 hours when it is most cost effective to do so and the service addresses the consumer’s needs identified in the community support plan. Out-of-home respite care is limited to 30 consecutive days per respite stay in accordance with the community support plan. In addition, lower payment rates should be negotiated for respite provided in a group setting (e.g., adult foster care or others).

IV. CONSUMER-DIRECTED RESPITE SERVICES

Consumer-directed respite services are available to a family caregiver for the unpaid care provided to a consumer under EW and AC programs. Consumer-directed respite services allow caregivers more choice, control, flexibility, and responsibility over the respite services they want and need. With this option, family caregivers select, hire and manage the respite workers as well as define what, when, and how the respite services are provided. Family caregivers can use consumer-directed respite services as a part of a Consumer Directed Community Support (CDCS) plan, as a service component of a traditional community support plan, or using Title III-E Older Americans Act or other grant funding.

As Service Component of the Community Support Plan:

For family caregivers of persons using EW or AC programs but not opting for CDCS, consumer-directed respite can be authorized and billed under the in-home respite billing codes (S5150, S5151) or out-of-home billing codes (S5150 with modifier UB, H0045). A separate line item is entered on the MMIS service agreement and the cost of this service is included within the care recipient’s case mix cap amount.
Here are some considerations for hiring workers:

- **Consumer directed respite services** may be provided in or out of the EW or AC recipient’s home. However, for consumer-directed out-of-home services this option does not allow caregivers to hire workers who are in the business or practice of providing respite services or a service offering respite outcomes (e.g., personal care assistance, adult day services or adult foster care). Instead, the provider may be a relative, friend or neighbor. For out-of-home respite the case manager should determine (1) if the residence or site is safe and appropriate; (2) whether the lead agency or other agency will act as employer of the respite worker; and (3) whether the lead agency or other agency will be the enrolled provider authorized to bill for the service.

- Respite workers must be able to demonstrate to the family caregiver and the EW or AC case manager or care coordinator their competence in providing respite care services. In all cases, the ability and skill level of the respite worker is evaluated against the care recipient's individual needs and preferences. The worker must be capable of implementing the established plan for addressing assessed health and safety needs.

- Respite workers chosen by the consumer must be hired by a provider agency that is under contract with the lead agency (e.g., Agency with Choice). Only in rare situations should respite workers be considered independent contractors. Case managers and care coordinators may also contract with a fiscal support entity. Only enrolled providers authorized to provide the services may bill for it. In consultation with the case manager/care coordinator and the Agency with Choice provider, the caregiver establishes the rate of pay for the respite worker. Payment rates are based upon available funds, scope and complexity of duties, worker skills and experience.

- Case managers/care coordinators need to inform the family caregiver of their role and responsibilities in managing the respite worker and in evaluating service outcomes. The recipient’s plan should detail the tasks and responsibilities of the respite worker. The caregiver establishes a job description for the respite worker that includes the rate of pay and hours of work.

**Consumer-Directed Community Support (CDCS) Services**

Consumer-directed respite is also available to persons as a part of the CDCS service delivery option. All of the policies and procedures for CDCS apply. Consumer directed respite services are detailed in the recipient’s community support plan and included within the CDCS budget amount. Under CDCS, the Fiscal Support Entity (FSE) is the enrolled provider, bills for consumer directed services and pays the respite worker. For more information on hiring this kind of respite worker and the CDCS option see the
V. USING FORMAL SERVICES FOR RESPITE OUTCOMES

There are formal home and community-based services for the care recipient that also offer a “respite” outcome to family caregivers (e.g., companion, adult day care). These services primarily provide a distinct set of supports to meet the recipient’s needs and should be established and billed as such and not as respite.

1. Companion Services

Companions provide non-medical care, supervision, and socialization type services in accordance with a therapeutic goal identified in the community support plan. Services may be provided by paid workers or volunteers from a social service or quasi-formal agency. Examples of these organizations include: R.S.V.P., Senior Companions, faith-based providers, LAH/BNPs. Use of this service can sometimes decrease the dependence on more costly long-term care services (e.g., skilled nursing, home health aide). Funding streams include: federal and state monies for Senior Companion Program, EW, AC, state grants, Title III, and private pay. Use billing code S5135 (15-minute unit) for EW and AC clients.

- Companions may also assist or supervise the person with meal preparation, laundry, and shopping, but not as a discrete service.
- The service may be provided in a private residence, public setting, or licensed sites (e.g., Adult Foster Care).
- Companions may be an escort for rides for those using public or private transportation services, or to other community programs such as church clubs, group respite programs. (Note: Those who need assistance with personal care while attending community programs and activities may qualify for personal care assistance services instead of companion.)
- Established senior companion programs maintain liability and auto insurance coverage for volunteer workers.

2. Adult Day Services (ADS)

Adult day services is a program operating less than 24 hours per day that provides functionally impaired adults with an individualized and coordinated set of services including health services, social services, and nutritional services that are directed at maintaining or improving the participants’ capabilities for self-care. Adult day services
vary in hours of operation, type of services and level of care provided. The type of care provided needs to address the individual’s needs outlined in the community support plan.

Programs primarily established for purposes of socialization or cultural integration that do not offer a coordinated set of health, social services, and nutritional services cannot be billed as adult day services. Services of this kind are considered to be group respite programs, senior centers, social or cultural programs or clubs.

Adult day services are established under Minnesota Statutes, Sections 245A.01 through 245A.16. Providers must meet one of the following criteria for EW and AC payment:

- Adult day services provided in the license holder’s primary residence, when the license holder is the primary provider of care, must be licensed under Minnesota Statutes, Section 245A.143.

- Adult day services provided in a nursing home, hospital or boarding care home licensed by the commissioner of health that regularly provider adult day for five or fewer functionally impaired adults at any given time who are not residents or patients of the nursing home, hospital, or boarding care home as defined in Minnesota Rules, parts 9555.9600 - 9555.9730.

- Adult day services provided in any other location must be licensed under Minnesota Rules, parts 9555.9600 to 9555.9730.

**ADS may be billed under codes S5100 (15-minute unit), S5100 Modifier TF (ADS bath – 15 minute unit), or S5102 (daily rate).** The provider cannot use both the 15-minute and daily rate for the same EW or AC recipient on the same day. The **ADS FADS code is S5100 or S5102 with a U7 modifier.** Rates and limits for charging daily or 15-minute units are established in contracts with the lead agencies counties and authorized per individual.

Transportation to and from the ADS may be billed under these codes for EW and AC recipients: **T2003 with modifier UC (EW) and T2003 (AC) for a one way trip.** However, friends, families, neighbors, volunteers, etc. should be used whenever possible to provide rides.

3. **Group Programs as a Respite Option – Not Billable under EW**

A group program is an informal or quasi-formal program established primarily for purposes of companionship, supervision, socialization, or community or cultural integration for frail or functionally impaired persons. This daytime program may also be a respite option for family caregivers.

These programs are typically found in small group settings and do not need to be licensed if they are not offering or providing a comprehensive set of health, social services, and
nutrition services (i.e. adult day services). Common sites for this type of program include faith-based organizations, senior or community centers, nutrition sites or a senior housing campus. This type of service can be very useful to family caregivers and may be offered on a sliding fee scale or donation basis. Group programs or group respite is not a billable service under EW. However, group respite may be billed as a discretionary service under AC with approval of the Commissioner. See the AC Annual Allocations Bulletin (#07-25-03) regarding discretionary services and applications http://www.dhs.state.mn.us/main/groups/publications/documents/pub/dhs16_138758.pdf

Group respite programs offering or performing services as specified within the adult day services definition need to be licensed. For more information on adult day licensure contact: DHS Licensing Division at (651) 296-3971.

LEGAL AUTHORITY

Minnesota Statutes Section 245A.02, subdivisions 2a and 15; Section 245A.11; Section 245A.143; Section 256B.0915; Section 256B.0913; Minnesota Rules, Parts 9555.9600-9730; Parts 9555.5105-9555.6265
Minnesota Legislation and Bill Status http://www.leg.state.mn.us/leg/legis.asp

RESOURCES

MHCP Provider Manual Chapter 26A MHCP Provider Manual
CDCS Lead Agency Manual http://edocs.dhs.state.mn.us/lfservlet/legacy/DHS-4270-ENG
Minnesota Help.info® Website: MinnesotaHelp.info - online public information and referral portal

SPECIAL NEEDS

This information is available in other forms to people with disabilities by contacting us at 651-431-2590, toll free at 1-800-882-6262 or through the Minnesota Relay Service at 1-800-627-3529 (TDD), 7-1-1 or 1-877-627-3848 (speech to speech relay service).