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Center for Workers with Disabilities  
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# Providing Personal Assistance Services Through a Medicaid State Plan Option

THE CENTER FOR WORKERS WITH DISABILITIES



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## Executive Summary

The Ticket to Work and Work Incentives Improvement Act of 1999 places particular importance on making Personal Assistance Services (PAS) available for persons with disabilities who want to live independently and enter or rejoin the workforce. The Act provides grants to states to develop state Medicaid infrastructures to support working individuals with disabilities. However, no state may receive a grant unless it makes personal assistance services available under their Medicaid State Plan.

The Centers for Medicare and Medicaid Services (CMS) has determined that a state is fully eligible to receive grant funds if it offers personal assistance services statewide, within and outside the home in an amount that allows a person to be engaged in full time competitive employment. This requirement can be met through the personal care Medicaid State Plan Option, Medicaid waivers, or a combination of the two.

As states look at the feasibility of adding or expanding the personal care option to their Medicaid program, a major consideration is the cost of such changes. Recently states have experienced significant

growth in both the number of persons receiving Medicaid and the cost of services provided by the program. The personal care option is no exception. From 1998 through 2003, nationally, the program almost doubled in expenditures from \$3.5 billion to \$6.3 billion.

States have used a variety of mechanisms to control the cost of personal care. These include requiring prior authorization, targeting the service to particular conditions or diagnoses, or limiting the number of hours of service.

To make PAS a viable support for employment and to satisfy the Medicaid Infrastructure Grant (MIG) requirements, some states like Utah and New Jersey have amended their current Personal Care State Plan Option to provide more hours of service both in and out of the home for person with disabilities who are working. California passed legislation to ensure their existing Personal Care State Plan Option program is available, not only in the home but also in the work place. Iowa is an example of a state that does not have a Personal Care Medicaid State Plan Option. They did an extensive study with recommendations to add the service but ultimately found the cost was too high.

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## Introduction

The purpose of this paper is to analyze how some states are providing personal assistance services (PAS) through a personal care Medicaid State Plan Option (SPO) to persons with disabilities who are eligible for participation in the Medicaid Buy-In program. It will include an examination of how the SPO for personal care has evolved to include services necessary for persons with disabilities to go to work. The paper looks at specific examples of legislation, State Plans, State Plan amendments, and administrative rules for personal care programs. It also looks at implementation manuals that have been developed to expand the personal care option to meet both the needs of persons with disabilities who want to go to work and the requirements established in the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). Finally, the paper includes the recommendations of one state's in depth analysis of whether to add personal care to its Medicaid State Plan.

## Background

The concept of personal assistance services has evolved over time. In general, it represents a service that is not purely medical in nature, but bridges both medical and social needs of a person. Funding sources such as Medicaid have come to recognize that acute and primary care medical services cannot always address the needs of individuals who have chronic conditions. A body of services has been developed to help individuals function in home and community settings by providing support so they can perform necessary activities of daily living (ADLs). These activities vary among programs but often include assistance with mobility, bathing, grooming, dressing, bowel and bladder care, repositioning and transferring, eating and assurance of adequate fluid intake, and assistance with self-administration of medications.

In the development of policy, several terms and definitions of PAS are used. Personal care, personal attendant care, attendant care, in-home services are all examples of terms used to describe personal assistance services. To complicate matters other services are often available as either a subset or part of personal assistance services. These include housekeeper services, homemaker services, and chore services.

## The Ticket to Work and Work Incentives Improvement Act of 1999

A key component of The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) is the recognition of the importance of access to health care for persons with disabilities who want to go to work. The Act points out that one of the most significant barriers for persons with disabilities to enter the work force is the fear of losing health care that is provided by public sources such as Medicaid and Medicare. The importance of PAS to persons with disabilities is also emphasized in the Findings and Purposes of the Act:

“Personal assistance services . . . remove many of the barriers between significant disability and work. Coverage for such services . . . are powerful and proven tools for individuals with significant disabilities to obtain and retain employment.” (Sec. 2 (a) (4) of the Ticket to Work and Work Incentives Improvement Act)

Consumers and advocates for persons with disabilities have long recognized that PAS is an example of an essential service for persons with severe disabilities who want to participate in employment, but is not available except through public programs such as Medicaid.

## Medicaid Infrastructure Grants

The TWWIIA authorizes the Secretary of Health Human Services to award grants to states to encourage the development of Medicaid Buy-In programs. These grants are intended to support states in the development of infrastructures that provide items and services to support working persons with disabilities. However, the legislation goes on to say:

“No State may receive a grant . . . unless the State demonstrates to the satisfaction of the Secretary that the State makes personal assistance services available under the State plan under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) to the extent necessary to enable individuals with disabilities to remain employed . . .”

“Employed” is defined as: “earning at least the applicable minimum wage requirement under section 6 of the Fair Labor Standards Act (29 U.S.C. 206) and working at least 40 hours per month; or being engaged in a work effort that meets substantial and reasonable threshold criteria for hours worked, wages, or other measures, as defined and approved by the Secretary.”

Personal Assistance Services is defined as:

“ . . . a range of services, provided by 1 or more persons, designed to assist an individual with a disability to perform daily activities on and off the job that the individual would typically perform if the individual did not have a disability. Such services shall be designed to increase the individuals control in life and ability to perform everyday activities on or off the job.” (Title II, Sec. 203 (b) (2) (B) of the Ticket to Work and Work Incentives Improvement Act)

This is not a definition used in Medicaid, however. It is taken from The Rehabilitation Act of 1973, as amended. This Act is the enabling legislation for Vocational Rehabilitation programs at the federal and state level.

The Centers for Medicare and Medicaid Services (CMS) administers the Medicaid Infrastructure Grant program. CMS established the following criteria for states to meet the PAS requirement of the Act regarding Medicaid Infrastructure Grants (MIG):

“For full eligibility under this grant program, entitling a state to receive multiple year funding, a state must offer personal assistance services statewide within and outside the home to the extent necessary to enable an individual to be engaged in full-time competitive employment.” (2006 Edition-Announcement Medicaid Infrastructure Grant To Support the Competitive Employment of People with Disabilities, page 31)

This requirement can be met through the Personal Care Medicaid State Plan Option, Medicaid waivers, or a combination of State Plan and waiver services.

A state can use their SPO personal care program to meet full eligibility:

“ . . . if it has a state plan personal assistance service that does not have individual limits that would preclude it from serving a person with a significant disability who is employed 40 hours per week. In that regard, services must be available inside and outside the home and cannot be limited to assistance in transportation to medical appointments. Additionally, the service cannot be limited to persons with a particular type of disability or level of disability. If a state reaches the fully eligible criteria based on its state plan service, waivers are not considered.” (2006 Edition-Announcement Medicaid Infrastructure Grant to Support the Competitive Employment of People with Disabilities, page 32)

### **Medicaid Personal Care State Plan Option**

States must provide certain Medicaid services to persons who are categorically eligible for the program. Examples of mandatory services include inpatient and outpatient hospital services, physician services, nursing facility services, and early and periodic screening, diagnosis, and treatment (ESPDT) for children under the age of 21. In addition to the mandatory Medicaid services, States may opt to provide other services in their Medicaid benefit package. Examples of these optional services include chiropractors, optometrists, psychologists, private duty nursing, dental, physical therapy, and eyeglasses.

Personal care is one of the optional services a state can elect to provide. If a state opts to provide an additional service or change a current optional service, they must amend their Medicaid State Plan and provide information on the amount, duration and scope of the service of the new or changed service. This includes documenting any limitations the state decides to impose on the service. The State Plan Amendment must be approved by CMS. Funding for the service is a combination of state dollars matched by federal dollars at a rate that is individualized to each state.

According to CMS, as of March 31, 2005, 35 States and District of Columbia provided personal care as a Medicaid State Plan Option service.<sup>1</sup> Personal care as an optional service is defined by CMS as follows:

“Personal care services (also known in States by other names such as personal attendant services, personal assistance services, or attendant care services, etc.) covered under a State’s program may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages which enables them to accomplish tasks that they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cuing so that the person performs the task by him/her self. Such assistance most often relates to performance of ADLs [Activities of Daily Living] and IADLs [Instrumental Activities of Daily Living]. ADLs include eating, bathing, dressing, toileting, transferring, and maintaining continence. IADLs capture more complex life activities and include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.” (Centers for Medicare and Medicaid, State Medicaid Manual, Section 4480, (C))

The personal care SPO was originally only available if it was provided to a recipient in their own home. The service could only be authorized by a physician. In this way, the Medicaid personal care program very much mirrored the home health benefit in Medicare and Medicaid (to receive those services, the recipient had to be home bound). However, the Omnibus Budget Reconciliation Act of 1993 significantly broadened where the personal care service could be provided and how the service could be authorized. In 1997, CMS promulgated the final rules governing personal care:

“Personal care services may now be furnished in any setting except inpatient hospitals, nursing facilities, intermediate care facilities for the mentally retarded, or institutions for mental disease. States choosing to provide personal care services may provide those services in the individual’s home, and, if the State so chooses, in settings outside the home.” (CMS, State Medicaid Manual, Section 4480, (B))

It is this broadening of the personal care option to include services outside the home that makes it possible for the Medicaid definition of personal care to match up with the definition of personal assistance services in the TWWIIA that requires the service to be available “on and off the job.”

### Costs of Personal Care State Option Programs

As states look at the feasibility of either adding or expanding the personal care option to their Medicaid program, a major consideration is the cost of such changes. From 1998 through 2003, many states that provided the personal care state plan option experienced significant growth in the program. Nationally, the program almost doubled in expenditures from \$3.5 billion in 1998 to \$6.3 billion in 2003. During that time frame several states saw annual increases of over one hundred percent in their personal care programs. For example, Alaska’s expenditures increased 133% between 2001 and 2002 and 123% between 2002 and 2003. California’s expenditures increased 217% between 2000 and 2001. The percentage change nationally between 2000 and 2001 was 37.8%.<sup>2</sup>

These specific trends coupled with the general increase in overall Medicaid costs for the last several years have made it difficult for states to entertain the addition or expansion of personal care services.

<sup>1</sup> *Medicaid-At-a-Glance 2005, Centers for Medicare and Medicaid, pg 10*

<sup>2</sup> *Medicaid Long Term Care Expenditures, FY 2003, Burwell, Brian, Sredl, Kate, Eiken, Steve, Table C*



In 2003, national personal care spending was \$22 per capita. States with the highest per capita personal care spending were New York (\$114), Alaska (\$68), New Mexico (\$66), Massachusetts (\$51), and California (\$38).<sup>3</sup> In terms of utilization, in 2001, nationally, there were 1.9 Medicaid personal care participants per 1000 population. States with the highest Medicaid participants per 1000 population were Arkansas (8), Missouri (7.3), California (5.9), Michigan (5.5), and New York (4.7).<sup>4</sup>

### Limitations on Medicaid Personal Care Programs

The way states try to control the personal care program is by placing certain limits on the service. According to CMS, all states and the District of Columbia that provide personal care as a SPO impose some type of limitation on the program.

In October 2004, the Kaiser Family Foundation surveyed the 50 states and the District of Columbia on several aspects of SPO personal care services. The programs vary greatly, reflecting the latitude given to the states in designing these programs. This survey gathered information on types of limitations states have imposed on their personal care program.

### Prior Authorization

Most states require prior authorization before the service can be provided. And most require a needs assessment for the service and the development of a plan of care. Some further conditions include:

- Care must cost less than nursing facility care (District of Columbia);
- Care must be supervised by an RN (Kansas); and
- Care must be an alternative to nursing facility care (Missouri).

<sup>3</sup> AARP, *Across the States: Profiles of Long-Term Care 2004 Research Report*, Mary Jo Gibson, Steven Gregory, Ari N. Houser, Wendy Fox-Grage, AARP Public Policy Institute, pg 243

<sup>4</sup> *Ibid.*, pg 229

### Targeting by Diagnosis or Condition

Some states have targeted their personal care program to persons with specific diagnoses or conditions. For example:

- In Rhode Island personal care is limited to mentally ill in residential facilities with fewer than 17 beds.
- In New Hampshire beneficiaries must be chronically wheelchair bound.
- In Kansas eligibility is limited to individuals with Severe and Persistent Mental Illness.

### Limiting Hours of Service

Some states provide SPO personal care services based on the assessment of need and do not have specific limitations on the number of hours provided. According to the CMS Ticket to Work reporting website, New Mexico, New York, and Massachusetts are examples of states that administer their SPO program this way. Other states do assessments of need but also choose to specifically limit the number of hours a person can receive through the SPO program. These limitations can be for a day, a month, and in the case of the District of Columbia, for the year. Some examples from the 2004 Kaiser Family Foundation survey:

- California: 283 hours per month;
- West Virginia: 220 hours per month;
- Nebraska: 40 hours per week;
- District of Columbia: 8 hours per day up to 1040 hours per year;
- Alaska: 8 hours per day up to 35 hours per week;
- Arkansas: 64 hours per month;
- Idaho: 16 hours per week;
- North Carolina: 3.5 hours per day up to 60 hours for the month;
- South Dakota: 120 hours every 3 months; and
- Maine: 2-4 hours per week.

**The Personal Care State Plan Option (SPO)**

The following are examples of how states have changed their existing State Plan Option personal care programs to include the needs of persons with disabilities who go to work and need PAS in the work place. California, Utah, Maryland, and Nebraska are fully eligible states in terms of the Medicaid Infrastructure Grant. New Jersey is conditionally eligible.

**Legislation**

The following excerpts are from legislation that California developed to expand the personal care option to include services for persons with disabilities who are working. The legislation not only includes services so a person can retain employment but also includes services for the person to obtain employment or return to work. The services cannot supplant services that are required by the employer to achieve reasonable accommodation, and are limited to those services authorized in the person’s home (so no new services are added because the person is employed). In California, a person can receive a total of 283 hours per month of personal care services. This legislation makes it clear that if a person is working, the total number of hours per month of personal care they can receive in the home and in the work place is 283.

**CALIFORNIA**

**Assembly Bill No. 925**

**Passed the Assembly August 30, 2002**

**Sec. 6**

- (c) Personal care services shall mean all of the following:
  - (1) Assistance with ambulation.
  - (2) Bathing, oral hygiene, and grooming.
  - (3) Dressing.
  - (4) Care and assistance with prosthetic devices.
  - (5) Bowel, bladder, and menstrual care.
  - (6) Repositioning, skin care, range of motion exercises, and transfers.
  - (7) Feeding and assurance of adequate fluid intake.
  - (8) Respiration.
  - (9) Assistance with self-administration of medications.

- (d) Personal care services are available if these services are provided in the beneficiary’s home and other locations as may be authorized by the director. Among the locations that may be authorized by the director under this paragraph is the recipient’s place of employment if all of the following conditions are met:

- (1) The personal care services are limited to those that are currently authorized for a recipient in the recipient’s home and those services are to be utilized by the recipient at the recipient’s place of employment to enable the recipient to obtain, retain, or return to work. Authorized services utilized by the recipient at the recipient’s place of employment shall be services that are relevant and necessary in supporting and maintaining employment. However, workplace services shall not be used to supplant any reasonable accommodations required of an employer by the Americans with Disabilities Act (42 U.S.C. Sec. 12101 et seq.; ADA) or other legal entitlements or third-party obligations.
- (2) The provision of personal care services at the recipient’s place of employment shall be authorized only to the extent that the total hours utilized at the workplace are within the total personal care services hours authorized for the recipient in the home. Additional personal care services hours may not be authorized in connection with a recipient’s employment.

**Sec. 8**

- (g) A beneficiary who is eligible for assistance under this section shall receive services that do not exceed 283 hours per month of personal care services.



### State Plan Amendments

This next example shows the current limitations on New Jersey's Medicaid personal care program. The service is available only in the beneficiary's home and limited to only 25 hours of service a week. Hours beyond the 25 must be for a medical reason and authorized by staff.

#### STATE PLAN UNDER TITLE XIX OF THE SOCIAL SECURITY ACT

Limitations on Amount, Duration and Scope of Services Provided to Medically Needy Groups

PREGNANT WOMEN, DEPENDENT CHILDREN, AND THE AGED, BLIND, OR DISABLED

23(f) Personal Care Assistant Service, in a Beneficiary's Home in the Community:

Personal Care Assistant Services are available to all three coverage groups (pregnant women, dependent children, and the aged, blind or disabled).

Personal care assistant services in this setting are limited to a maximum of 25 hours per week. If there is a medical need for additional hours of service, this limit may be exceeded by the providers, in consultation with the Medicaid District Office (MDO) staff, up to an additional 15 hours per week. More than 40 hours of personal care assistant services may be provided under exceptional and extreme circumstances of medical necessity with written MDO approval.

Personal care assistant services are provided by certified licensed home health agencies or by accredited homemaker agencies.

Medicaid District Office staff periodically and on an ongoing basis shall perform case management and conduct post-payment quality assurance reviews of recipient services to evaluate the appropriateness and quality of personal care assistant services. The findings shall be communicated to the provider and may result in an increase, reduction or termination of services.

Monitoring visits also shall be made by Division staff to the agency to review compliance with personnel, record keeping and service delivery requirements. Continued noncompliance with requirements shall result in such sanctions as curtailment of new recipients for services, suspension or rescission of the provider contract.

Personal care assistant services are not provided in a residential health care facility or a licensed Class C boarding home.

Personal care assistant service provided by a family member (as defined by HCFA) is not a covered service.

The following is a recently approved amendment to the New Jersey Medicaid State Plan that expands the provision of personal care assistant services beyond the residence to include a beneficiary's place of employment. New Jersey further expands the benefit to include personal care assistant services provided in a prevocational or educational setting if the beneficiary is preparing for employment. The hourly limitation is increased to a maximum of 40 hours per week whether it is provided in or out of the home. New Jersey has opted to provide this service to persons who are either categorically eligible for Medicaid or eligible for their medically needy program.

#### STATE PLAN UNDER TITLE XIX OF THE SOCIAL SECURITY ACT

Limitations on Amount, Duration and Scope of Services

Provided to the Categorically Needy

24(f) Personal Care Assistant Home or Community-Based Services

Personal care assistant services are available to the categorically needy.

- (1) Personal care assistant services to the categorically needy in the home or community must be prior authorized. Personal care assistant services may be provided in the beneficiary's residence or at their place of employment. Personal care assistant services may also be provided in a prevocational or

educational setting where the beneficiary is preparing for employment. Prior authorization for all personal care assistant services, regardless of whether they are provided in the home or in the community, must be obtained by the provider agency from the Division of Disability Services before service is initiated. Services are limited to a maximum of forty (40) hours per week.

- (2) Personal care assistant services for EPSDT-eligible persons may be provided in settings other than the individual's residence and are also subject to the requirement for prior authorization by the Division of Disability Services.
- (3) Personal care assistant services are provided by certified, licensed home health agencies or by registered, accredited health care services firms, enrolled as NJ Medicaid providers. Health care services firms must maintain a valid accreditation with one of the accrediting bodies recognized by the Division of Disability Services.
- (4) Division of Disability Services staff periodically visits beneficiaries to conduct reviews of personal care assistant services to evaluate the appropriateness and quality of the services. The findings of such reviews may result in an increase, reduction or termination of services. Such determinations shall be communicated to the provider agency.
- (5) Monitoring visits shall also be made to personal care assistant provider agencies [the agency] by Division of Disability Services staff and the accrediting body to review compliance with personnel, record keeping and service delivery requirements. Continued non-compliance with requirements shall result in sanctions such as curtailment of the authorization of services for new beneficiaries for personal care assistant services, suspension or rescission of the provider contract. Loss of accreditation will result in immediate termination of the PCA provider agency from the NJ Medicaid program.
- (6) Personal care assistant services are not provided in nursing facilities, hospitals, residential health care facilities, licensed Class C boarding homes, adult or pediatric day health care centers, assisted living facilities, Division of Developmental Disabilities congregate living facilities or Traumatic Brain Injury Waiver community residential services facilities.
- (7) Personal care assistant services provided by a legally responsible relative (as defined by CMS) are prohibited and will not be reimbursed. Exceptions for other family members or relatives to provide personal care assistant services may be granted on a case-by-case basis at the discretion of the Director of the Division of Disability Services, if requested by the PCA provider agency. In all instances the individual must be (1) a currently certified home-maker/home health aide, (2) an employee of the agency and (3) directly supervised by a PCA provider agency registered nurse. Such exceptions must be renewed every six months.

In another example, Utah has an existing home based personal care program. The program is limited to services in the recipient's home and is also limited to 60 hours per month. Utah amended their State Plan to include Employment Related Personal Care Services. The personal care service specifically targets persons with disabilities and is intended to provide support for integrated employment opportunities. There is a strong emphasis on case management functions that enhance access and coordination of employment and education supports at the work site as well as providing access and coordination to other Medicaid services. The amendment is limited to services outside the home that are necessary to help them obtain or retain competitive employment. Competitive employment is defined as at least 40 hours per month.

Utah's SPO is not available to recipients who are enrolled in any 1915(c) waiver if personal care services are a covered service being utilized by the recipient.

The following language is from Utah’s State Plan Option.

**HOME-BASED PERSONAL CARE SERVICES**

Home-based personal care services are covered benefits when provided by an agency licensed to provide personal care services outside of a 24-hour supervised living setting, in accordance with Utah Code Annotated, Title 26, Chapter 21. The services are delivered by a personal care aide or a home health aide (performing only personal care level tasks) who has obtained a certificate of completion from the State Office of Education, or a licensed practical nurse, or a licensed registered nurse.

*Limitations*

- (1) Home-based personal care services are covered benefits when prescribed by a physician
- (2) Home-based personal care services are not covered benefits: (a) for recipient’s residing in an institution, or (b) when delivered currently with Medicaid home health aide services.
- (3) Home-based personal care services are limited to 60 hours per month.

**EMPLOYMENT-RELATED PERSONAL CARE SERVICES**

Employment-related personal care services are covered benefits provided to support integrated employment opportunities for individuals with a moderate to severe level of disabilities. Services are delivered by an agency licensed to provide personal care services outside of a 24-hour supervised living setting, in accordance with Utah Code Annotated, Title 26, Chapter 21, or a non-agency individual employed by the recipient as a personal care assistant who meets provider qualifications established by the Medicaid Agency. Employment-related personal care services include physical assistance and cognitive cuing to direct self-performance of necessary activities.

*Limitations*

- (A) Employment-related personal care services are covered benefits only for recipients who:

- (1) meet the disability definition of the SEC 1614 [42 U.S.C., 1382c](a)(3), and
- (2) are gainfully employed in an integrated community setting.
- (B) Employment-related personal care services are limited to:
  - (1) assistance with daily living activities;
  - (2) assistance with instrumental activities of daily living;
  - (3) transportation to and from the worksite;
  - (4) case management support to access and coordinate services and supports available at the work site through education, vocational rehabilitation, and other work-related public programs, and
  - (5) case management support to access and coordinate employment-related personal care services with other Medicaid State Plan services, including home-based personal care services;
  - (6) services provided to eligible individuals outside the home necessary to assist them in obtaining and retaining competitive employment of at least 40 hours per month. Services are designed to assist an individual with a disability to perform daily activities on and off the job that the individual would typically perform if they did not have a disability.
- (C) Employment-related personal care services are not covered benefits:
  - (1) when provided by a legally responsible family member or guardian;
  - (2) when provided to individuals residing in hospitals, nursing facilities, ICFs/MR, when the recipient is employed by the facility, or
  - (3) when provided to individuals enrolled in a 1915(c) Home and Community-Based Services waiver when personal care services are provided as a component of a covered waiver services currently by being utilized by the recipient.

- (D) Scope, amount and duration of employment-related personal care services will be determined on an individual recipient basis through a needs assessment process approved by the Department and completed by staff of the Department or its designee.
- (E) Scope, amount and duration of employment-related personal care services will be authorized through completion of a written individualized service plan prepared jointly by the individual recipient and the Department staff or designee conducting the needs assessment.
- (F) Non-agency personal care assistants employed by the recipient to provide employment-related personal care services are required to utilize a Department approved fiscal intermediary to coordinate Medicaid claims submittal and payment and to coordinate payment of employer-based taxes.
- (G) Recipients who cannot direct the activities of a personal care assistance employee may designate a proxy to act in this capacity within parameters established by the Department.

The workplace is defined as “the physical location where a recipient engages in gainful employment.” (Title 10.01 (31))

Maryland requires case monitors visit the workplace as needed but not less than 4 month intervals to review the plan of care, the interaction and relationship between the recipient and the personal care aide, and the personal care aide’s performance and ability to give the required service. (Title 10.04 D-1)

**NEBRASKA**

Nebraska provides personal assistance services to persons outside their home, specifically at the person’s worksite if the person is engaged in competitive integrated employment that is defined as working a minimum of 40 hours at minimum wage. Nebraska makes an important clarification in that the personal assistance services provided at the worksite cannot include tasks which perform the job the client was hired to do. Nebraska also recognizes that persons who are competitively employed and reside in a licensed residential program that provides personal assistance services as part of the program can receive additional personal assistance service at the worksite.

**Examples of Administrative Rules to Implement SPO Personal Care for Persons with Disabilities who are Working**

**MARYLAND**

The following example of administrative rules is taken from Title 10 of the Maryland Department of Health and Mental Hygiene Code Regulations for Personal Care Services. Maryland expanded their State Plan personal care program to include services provided outside the home but only services provided in the workplace. Maryland does not define work by any number of hours but uses the following definitions:

“Gainful employment” means work where income or wages are reported to the Internal Revenue Service. (Title 10.01 (8-1))

**Excerpts From the Nebraska Health and Human Services Finance and Support Manual 471 Chapter 15 Personal Assistance Services**

**15-002 Definitions of Terms:**

Competitive integrated employment means working a minimum of 40 hours per month at minimum wage.

**15-003.01C Services Outside a Client’s Home:**

Personal assistance services may be provided outside of a client’s home, including at the client’s worksite when the client is engaged in competitive integrated employment. Services provided may only include those authorized tasks that might otherwise be needed in the home and community (for example, assistance with toileting or eating a meal), and if at a

worksite, may not be tasks which essentially perform the job the client was hired to do (for example, job coaching). Accompanying and assisting the client with needed services when the client has work-related travels is also allowable.

#### 15-004.01 Eligibility Criteria

To be eligible for personal assistance services, a client must meet all of the following criteria:

- (1) Is a current Medicaid client;
- (2) Needs personal assistance services to live in the community;
- (3) Does not have needs that require more intensive services than those listed in 471 NAC 15-003.01 due to an acute health care level;
- (4) Is not receiving or eligible for personal assistance services or similar staff support based on their residence or place of employment. (An individual residing in a licensed residential service program may only be eligible for personal assistance services under this regulation if it is needed to maintain competitive integrated employment . . .)

### Adding a New Medicaid Personal Care State Plan Option

#### IOWA

In each of the previous examples, the state had a SPO personal care program and opted to expand the program. Iowa is a state that has a Home and Community Based waiver program but does not have a Personal Care State Plan service. In October of 2000, Iowa convened a work group to look at the feasibility of adding a Personal Care State Plan service to their Medicaid program. The work group looked at several scenarios trying to ultimately develop a model that would be fiscally feasible but not be so limiting that it would exclude large numbers of persons who might need the service. Iowa concluded that the two most important factors that should influence the ultimate design of the PAS program are 1) the level of care needed by persons qualifying for the benefit and 2) targeting persons

who would be interested in receiving the PAS benefit through a consumer directed care model. The model would include persons in their Medicaid Buy-In program who meet the level of care need and accept a consumer directed model. The work group did look at the possibility of requiring persons in the Buy-In to be working at least 40 hours a month, but decided the program could be controlled using the limitations of level of care and consumer direction so they did not include any work requirement in their recommendation. To date, Iowa has not implemented a PAS program. Like most states, the overall increases in Medicaid costs have impacted Iowa and has made it infeasible to add new Medicaid programs. The state has continued to look at the issue with the hope that the program may be able to be implemented in the future.

The following is the Executive Summary of the Iowa work group's final recommendations issued in August 2001. The process that Iowa went through may be useful to any state that is thinking about adding or expanding personal care in their State. Of particular interest may be the assumptions that Iowa made in looking at the option, particularly factoring in the potential impact of including persons in their Buy-In program. Also, the process in which Iowa worked through the cost factors may be useful.

“The Medicaid Infrastructure Grant Work Group was convened in October, 2000 for the purposes of designing a Personal Assistance Service (PAS) optional state plan benefit. This report contains the work group's recommendation for the parameters of a PAS benefit. It is intended that the benefit would be implemented beginning January, 2003 (the second half of state fiscal year 2003). The work group recommends that the benefit would be extremely comprehensive with respect to covered services, expanded beyond the scope even of the current PAS benefit available through the state's home and community based waiver program. It would not only allow for the provision of PAS at home, but would enable a person who works to receive PAS in their workplace if this were necessary. The benefit would not have an hour per week or dollar



amount cap. However, there would be a pre-determined minimum number of hours per week that consumers could obtain PAS without going through a prior authorization process and beyond which, a process for obtaining authorization for additional hours. The work group also recommends that the benefit would be limited to those persons with a physical disability or diagnosis of chronic illness, who have also been assessed to have at least a moderate need for hands-on assistance with activities of daily living, and who are able to self-direct services. Last, it is recommended that the PAS services would only be available through a consumer-directed model, i.e., not available through provider agencies.

It is estimated that in state fiscal year 2003, the state's share of the projected new cost for this benefit would be \$1.6 million. In state fiscal year 2004, for the first full year of implementation of the new benefit, the projected new cost to the state would be \$6.9 million. It was also projected that there would be other costs associated with the implementation of the benefit. One such cost would be associated with a fiscal intermediary service to assist with the hiring, firing and fiscal responsibilities of employing one's own caregiver. If every person using PAS also opted to use the fiscal intermediary, the work group anticipates a state cost of \$185,000/month. Similarly, the work group recommends that anyone accessing the PAS benefit should also be entitled to access the state plan targeted case management benefit should they so desire and should they not already be entitled by virtue of a particular diagnosis (i.e., chronic mental illness, mental retardation or developmental disability) to be able to do so. It was roughly estimated that if all persons accessing the PAS benefit who don't currently have access to the targeted case management benefit were to seek targeted case management, it would mean an additional state cost of approximately \$37,000/month."

Iowa also wanted to develop a scope of services that reflected a comprehensive array of PAS services that could meet the broad range of needs that persons

might need. In their planning, Iowa particularly tried to address the specific PAS needs of persons who have gone to work.

#### **"Proposed State Plan PAS Benefit List of Covered Services**

In developing a recommended scope of services to include as the state plan PAS benefit, the work group considered the list of services included as PAS services in Iowa's HCBS waiver programs, the services provided in Iowa's PAS pilot and suggestions from other states. The work group felt that it was important for the list of services included as PAS services to be as comprehensive as allowable so that it was flexible enough to support the varying needs of all consumers who might access it. The work group also felt that it was critical to allow for PAS to be provided to persons at work as supported by the new federal Medicaid rules. The following list contains those services the work group felt should be included under the PAS state plan benefit. The work group intends to finalize the definitions, the criteria and the process by the end of the summer. At this point in time, the work group preliminarily recommends that the PAS benefit should include:

- hands-on assistance with ADLs . . . as well as supervision and cuing, and assistance with specific employment-related ADLs, such as assistance with combing hair, applying make-up, straightening clothes, eating lunch, and/or other activities of daily living throughout the work day and on business trips;
- washing (other than above);
- oral hygiene;
- ear, nose, foot, hair and skin care and hygiene;
- care of wounds or injuries;
- assistance with exercises;
- therapeutic activities;
- medication assistance;
- life support;
- meal preparation and meal clean-up;
- coverage for assistive devices;
- child care assistance (to be further defined);



- light housework;
- completion of the paperwork required for receiving personal assistance services;
- other special needs approved by the Division of Medical Services as being incidental to the care of the member;
- job-related assistance (i.e., work site activities), including:
  - (A) business travel companionship—providing assistance with making travel arrangements, completing travel reimbursement paperwork, serve as personal driver, facilitate the acquisition of chauffeuring services, and/or serve as a travel companion on business trips;
  - (B) assistance with office services—provide assistance with opening mail, making telephone calls, keeping workspace organized, making copies, filing, taking dictation, and entering data, and
  - (C) meeting assistance—provide interpreter services or facilitates the acquisition of an interpreter, voice interpretation, meeting note taker, and/or document reader.

**The PAS benefit would not include the following services:**

- job coaching, job teaching, transportation of a consumer to job interviews or supported employment activities;
- rehabilitation activities;
- performing the essential functions of the job;
- taking over the responsibilities or accommodations of employers;
- case management;
- personal assistance services provided by a spouse of the recipient, the parents or stepparents of a minor child, or a legally responsible relative;
- personal assistance services provided at the work site when a consumer is participating in a sheltered employment, work activity, enclave, or work crew, and
- personal assistance services provided when a consumer is residing in a medical institution.”

**Conclusions**

The Ticket to Work and Work Incentives Improvement Act and the accompanying Medicaid Infrastructure Grants that are authorized in the Act have a strong emphasis on providing PAS to persons who need that service to be able to go to work. Some states have expanded their SPO personal care programs to provide this essential service in the work place. This includes expanding the limitations of their current programs to insure the service is available to persons who can work full time. States have also designed their SPO programs to insure that the service focuses on the specific PAS needs of the individuals and does not supplant or support the specific requirements of the job.

States that do not currently have a SPO personal care program are confronted with some other factors if they want to add this service to their Medicaid program. The issues of cost and utilization are magnified beyond just the needs of persons who are eligible for a Medicaid Buy-In program. Iowa’s experience offers a good blue print for states that want to explore adding the new service. The comprehensive process that Iowa used is a way to address many of the unknowns that adding a new service presents.

There needs to be further research on just what is the utilization of Medicaid SPO personal care programs by persons in Medicaid Buy-In programs. This research needs to include not only the amount or service utilized and the costs, but also how much of the service is being utilized in the work place, how much is used in the home and what types and amounts of supportive services are needed by persons who need PAS to go to work.



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