

MaineCare Personal Assistance Services in the Workplace



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MaineCare Personal Assistance Services in the Workplace
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Background

“Personal care assistants are the pins to my life. They are just cornerstones; they need to be present.”¹

In the United States, an estimated 3.7 million people (almost 2 percent of the population) need assistance from another person to perform activities of daily living such as bathing, dressing and eating.² A survey of Maine households reported that 41 percent of those with a disability require personal assistance.³

In Maine, the use of personal assistance by people with disabilities has been a central focus of the CHOICES Project (Continuing Health Options and Incentives via Coordinated Employment Services), a Medicaid Infrastructure Grant from the Centers for Medicare and Medicaid Services (CMS). This Project has conducted qualitative and quantitative research on the use of assistance services, such as personal care, by people with disabilities in the context of the MaineCare Option for Workers with Disabilities (WWD Option). This option is a category of Medicaid that allows people with disabilities who are working to earn more money and still keep their MaineCare benefits.⁴

Findings from the Project’s work, as well as a preliminary analysis of MaineCare (Medicaid) policies, are presented in this report. The focus of the report is personal assistance services through MaineCare funding, with a specific focus on services in the workplace. This preliminary report is designed to provide a basis for further research needed to determine personal assistance needs, demand, cost, benefit, or the impact of policies or practices.

To help provide context for a discussion of these issues, the report uses a scenario involving a person with a disability who uses personal care and other assistance services on a daily basis. The scenario is a portrayal of a hypothetical person interested in returning to the workforce after a car accident that resulted in quadriplegia. Although the scenario is not real, it is realistic. Details of the scenario are based on a compilation of facts from case studies and interviews with working people who use personal assistance services.

¹ Vaughn, L., Evans, L., Gray, C. (2004) *Personal Assistance Services for Workers with Disabilities: Case Studies (2004)*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. <http://choices.muskie.usm.maine.edu/PAScasestudies.htm>

² Kennedy J, LaPlante M.P., Kaye H.S. *Need for Assistance in the Activities of Daily Living*. Disability Statistics Abstract. No. 18. June 1997. Accessed Oct. 29, 2004 <<http://www.dsc.ucsf.edu/pdf/abstract18.pdf>>.

³ Berkowitz, M. Honeycutt, T. (2002). Disability in Maine: 2002 (May 23, 2002).

⁴ MaineCare Option for Workers with Disabilities allows people with disabilities (who meet Social Security guidelines for having a disability) to earn up to 250% Federal Poverty Level (FPL) (earned and unearned income) and still keep their MaineCare. In 2004, 250% of FPL is \$1,940 per month for a single person.

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Personal Assistance Services and Personal Care

The terms personal assistance services (PAS) and personal care are sometimes used interchangeably to describe certain supportive services. In general, PAS can include any service provided by another person to assist people with disabilities to perform tasks that they would perform themselves if not for their disability.⁵

The federal government's Medicaid Manual for states defines personal care 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. Personal care services can be provided on a continuing basis or on episodic occasions. Skilled services that may be performed only by a health professional are not considered personal care services.”⁶

MaineCare service packages that cover personal care services generally use this definition, although with some limitations on tasks such as shopping and transportation. Some MaineCare service packages also cover such services as personal support, supported employment, and independent living skills services. Unless otherwise indicated, this report uses the term personal assistance services or “PAS” to refer to all of these MaineCare funded services.

The Scenario

The scenario presented below (in shaded sidebars) is designed to illustrate in personal terms a situation in which issues about MaineCare and personal care and other services become central to a person's life in the community.

⁵ Kennedy J, LaPlante M.P., Kaye H.S. *Need for Assistance in the Activities of Daily Living*. Disability Statistics Abstract. No. 18. June 1997. Accessed December 23, 2003 <<http://www.dsc.ucsf.edu/pdf/abstract18.pdf>>.

⁶ State Medicaid Manual, Part 4 – Services, Section 4480. Accessed Oct. 29, 2004 <http://www.cms.hhs.gov/manuals/pub45/pub_45.asp>.

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Access to Personal Assistance through MaineCare

There are several ways for people with disabilities to obtain personal care and other assistance services in Maine⁷. Individuals who pay for their own services can hire an assistant directly or through an agency provider. For those seeking publicly funded services, Maine offers several personal assistance service packages which vary by funding source, eligibility criteria, type of services, and sometimes provider type. Most publicly funded service packages are either paid for by MaineCare (Medicaid), which is a combination of federal and state funding, or entirely by state funds.⁸

Each publicly-funded personal assistance service package has a set of eligibility criteria. Eligibility usually depends on a person's financial status (income and assets), an assessment of assistance needs, the person's type of disability, and age. The service packages are described in Appendix A.

Financial Eligibility for Personal Assistance Services through MaineCare

Generally, a person's financial eligibility for MaineCare is considered first. There are several eligibility options for individuals with disabilities:

- ❖ If the person receives Supplemental Security Income (SSI)⁹, they are automatically eligible for full MaineCare benefits.
- ❖ If the person is in a certain group – such as having a disability, age 65 or older, being a child, or a single parent with children – and has higher income than allowed under the SSI category, there are several other eligibility categories, with the highest earning and asset limits found in the Workers with Disabilities Option (“working disabled” category).¹⁰
- ❖ A person might also become MaineCare eligible through one of the MaineCare categories for people who need facility level care,¹¹ which have specific financial limits that are about \$1,692 a month (217% of FPL in 2004).

Jack is a 41 year old man who lives alone in a rented apartment in Portland, Maine. He formerly worked as a salesperson. Jack has quadriplegia as the result of an automobile accident seven years ago. Jack uses personal care services to help with eating, moving between his bed and wheelchair, toileting, bathing, grooming and for a variety of housekeeping tasks. He receives a monthly payment from SSDI (Social Security Disability Insurance), and has health insurance from Medicare and MaineCare. His only income is from his SSDI payments, which are \$730 each month, so Jack is eligible for MaineCare through an eligibility category for people with disabilities with income under 100% of the federal poverty level (\$776 in 2004).

⁷ In limited circumstances, personal assistance services (PAS) can be provided through Vocational Rehabilitation (VR). Vocational Rehabilitation services are for people who have a physical or mental impairment which results in a substantial impediment to employment, and require VR services to prepare for, secure, retain or regain employment. PAS through VR funding is provided to assist a person with daily activities of living on or off the job site if required for employment. PAS are only provided if other VR services are being provided and other funding streams are sought in order to provide ongoing PAS.

⁸ Medicare, a federally funded insurance program, pays for some personal assistance services through its home health benefit under limited circumstances.

⁹ SSI is a Federal program run by the Social Security Administration. The program provides cash assistance to aged, blind, and disabled people who have very low incomes. Go to <http://www.socialsecurity.gov/notices/supplemental-security-income> for more information.

¹⁰ MaineCare Option for Workers with Disabilities allows people who meet Social Security guidelines for having a disability to earn up to 250% Federal Poverty Level (FPL) (\$1,940 a month for a single person in 2004) and still keep their MaineCare benefits.

¹¹ Nursing Facility or Intermediate Care Facility for Persons with Mental Retardation

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For those who do not meet the financial guidelines for MaineCare, personal assistance may still be available through other state-funded options, such as Home Based Care.¹²

Medical Eligibility for Personal Assistance Services through MaineCare

A person who is financially eligible for MaineCare services must also meet certain medical criteria related to their assistance needs to obtain PAS through one of the MaineCare service packages. Each service package serves people with different levels of assistance needs and offers different types of services.¹³

MaineCare personal assistance service packages fall into two categories – “state plan” services and “waiver” services. State plan services are available to all MaineCare enrollees who meet the need-level criteria for a specific personal assistance service package, which are generally moderate level needs. Waiver services are for individuals who have assistance needs extensive enough to qualify them for care in a nursing facility or other institution¹⁴. The waivers allow people who need facility-level care and meet financial guidelines to receive long-term services at home.¹⁵

Because Jack’s assistance needs are extensive, he is qualified as needing “nursing facility level care.” But he is able to live in his own apartment with personal care services he receives through the MaineCare Physically Disabled Waiver. Based on Jack’s need, the waiver program provides about 35 hours of personal care services in his home each week. Without these services, Jack would have to live in a nursing facility because he does not have the money to pay for the amount of services he needs to live at home.

Everyone who wants to receive publicly funded PAS in Maine must have an assessment of their assistance needs. MaineCare uses two assessment methods for determining someone’s needs. For most state plan and waiver service packages, when someone requests or is referred for an assessment, a nurse visits them to observe and ask questions about their daily tasks, assistance needs, informal supports, and other factors to determine eligibility and help create a plan for services. The nurse or therapist uses a standardized assessment tool called the Medical Eligibility Determination (MED). The assessment measures ADL and IADL needs and determines eligibility for different service packages offering personal care.

For service packages serving people with mental illness, mental retardation or developmental disabilities, MaineCare uses a person-centered planning process involving the consumer to determine a person’s needs and ways to meet those needs.

¹² Go to http://www.state.me.us/dhs/beas/nf/frequent/comm_opt.pdf for more information.

¹³ See Appendix A or long-term care community programs table, http://www.state.me.us/dhs/beas/nf/frequent/comm_opt.pdf

¹⁴ Intermediate Care Facility for Persons with Mental Retardation

¹⁵ For a listing of waiver options and their descriptions, see Appendix A.

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MaineCare Personal Assistance Service Packages

Number of People Served

In fiscal year 2003, there were over 42,000 people with disabilities in MaineCare, age 16-65 years old.¹⁶ More than 14,000 people age 16-65 used MaineCare service packages that offer personal assistance services. There were more than 3,300 people, age 16-65, who used personal assistance services offered in these service packages.

MaineCare Service Package	Number of People with Disabilities Using the Service Package Ages 16-65 Fiscal Year 2003¹⁷	Number Using PAS in the Service Package Ages 16-65 Fiscal Year 2003¹⁸
Private Duty Nursing/Personal Care Services	2,437	539
Home Health	1,667	265
Elderly and Adults with Disabilities Waiver	545	475
Physically Disabled Waiver (Consumer-Directed)	294	291
Consumer-Directed Attendant Services	254	254
Mental Retardation Waiver	2,176	1,371
Community Support Services	6,981	114
Total	14,354	3,309

¹⁶ Eligibility category: "Disabled".

¹⁷ Numbers are based on claims data for fiscal year 2003. People may be in more than one category of service.

¹⁸ There are a number of services, such as nursing, that can be included in each of these service packages, but are not represented in the table above. See Appendix D for list of services included in each of the service packages. Numbers are based on claims data for fiscal year 2003. People may be in more than one category of service.

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Hours and Cost of Services Available

The number of hours of personal assistance services available to someone on MaineCare depends on the service package and the individual's assistance needs. Some service packages, such as Home Health and the Mental Retardation Waiver, do not limit the number of hours available; hours are assigned based on a determination of need. Other service packages have limits on how many hours of assistance are available per week or month, either in terms of the cost of services or the weekly hours of services. These limits may vary depending on the level of need.

In a survey of people with disabilities on MaineCare through the Workers with Disabilities Option, an estimated one-half of those using paid PAS said they used fewer than five hours of paid PAS per week. Almost three out of four workers who said they used paid PAS reported they had enough hours of PAS.¹⁹

MaineCare enrollees pay \$5 per month as a co-payment for most non-waiver personal assistance services. For most waiver services, enrollees with income more than 125 percent of the Federal Poverty Level (\$970 in 2004), after certain deductions, disregards and allowances, pay a portion of their remaining income for services.²⁰

How Services are Delivered

Once an assessment helps determine what service package(s) a person is eligible for and what services they need, the individual (or someone they choose to make decisions for them) must decide how services will be delivered. Most publicly-funded PAS in Maine is delivered by a home care or other agency. The agency is given the approved number of hours and types of services as determined by the assessment. The agency will then work with the consumer to send the appropriate type of worker to deliver the services.²¹

Jack receives personal care assistance in his home through the MaineCare Physically Disabled Waiver. This option allows Jack to direct his own services, known as consumer-direction. Jack is responsible for hiring, supervising and paying his personal care attendants. Jack has hired two workers to help him. One person he found by placing an advertisement in the paper. The other person he hired is a long time friend. Between these two workers, Jack determines when a person comes in to give him services. He has also trained both workers how to do certain tasks he needs assistance with.

¹⁹ Salley, S. T., & Glantz, L. (2002). *The MaineCare Option for Workers with Disabilities: A survey of past and present enrollees*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=31.

²⁰ Long term care community programs. Accessed Oct. 29, 2004 <http://www.state.me.us/dhs/beas/nf/frequent/comm_opt.pdf>.

²¹ For publicly funded personal care service packages administered by the Bureau of Elder and Adult Services, Maine has a contract with Elder Independence of Maine (EIM) to coordinate the delivery of services. EIM works with over 200 home health, adult day services, personal care agencies and independent nurse contractors to deliver services. Go to <http://www.elderindependence.org> for more information.

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Many personal assistance users have the option of directing their own services, an option known as consumer direction. Consumer direction allows individuals to hire, supervise and pay their own personal attendant to provide services. Consumer-directed PAS is available through two MaineCare service packages – the MaineCare state plan Consumer-Directed Personal Care Attendant²² service package and the MaineCare Physically Disabled²³ Waiver service package.

People with Disabilities, Employment and Personal Assistance Services

Contrary to some expectations, people who have significant disabilities and are enrolled in MaineCare often hold down part-time or full-time jobs. Among people with disabilities enrolled in general MaineCare eligibility categories, about 12 percent said they worked.²⁴ Of those who worked, about 79 percent said they worked 10 hours per week or more.²⁵ In addition, there are more than 600 people enrolled in MaineCare for Workers with Disabilities, an eligibility category designed specifically for people with disabilities who work and earn too much money to qualify for other MaineCare categories.²⁶ In a survey of these enrollees who are currently working, 59 percent said they worked 20 hours per week or more.²⁷

Jack and his vocational counselor are talking about ways Jack can become self-employed, working at home. Through former co-workers, Jack has identified several opportunities for part-time work as an independent contractor. Jack cannot afford private insurance coverage so he knows it is important to maintain his MaineCare coverage. Once Jack starts working, he can continue to keep MaineCare as long as his total earnings and income are less than 250% of the Federal Poverty Level (\$1,940 in 2004).

²² Chapter 2, Section 12 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s012.doc>>.

²³ Chapter 2, Section 22 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s022.doc>>.

²⁴ Salley, S.T., & Glantz, L. (2004). *MaineCare Enrollees With Disabilities: Work Experience. Results from a 2002 Survey*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=524

²⁵ Salley, S.T., & Glantz, L. (2004). *MaineCare Enrollees With Disabilities: Work Experience. Results from a 2002 Survey*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=61

²⁶ As of June 30, 2004. Cumulatively, more than 2,100 people had enrolled in the MaineCare Workers with Disabilities Option since its beginning in August 1999 (8/99-12/03).

²⁷ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=345. While all members enrolled in MaineCare through the Workers with Disabilities Option are required to have earnings from a job, there are some who might be in transition from one job to another, and therefore are not “currently” employed.

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Survey results also indicate that work is important for people with disabilities, for many reasons. People expressed views of work as a way to “feel better about myself” and “to feel like I’m contributing”. It is also a way “to better support my kids and get out of the house”. For those who are working, increasing the number of hours of work are ways for a person to “be self-sufficient”. Other reasons for increasing hours include:²⁸

- ❖ “To get something I like better: higher paid/more skilled job using [my] computer skill.”
- ❖ “To move off from disability to a full time work schedule.”
- ❖ “So that I can buy a car and go to school to become more independent.”

Working provides motivation, identity, personal and financial stability, and growth opportunities for many people. It is often an important part of one’s place in the community. People using personal assistance services have said work is an integral part of daily functioning to accomplish goals they have set for themselves.²⁹

Using Personal Assistance Services to Support Work

A working person with a physical disability, such as Jack in the scenario described above, might use PAS at home to help get ready for work – to get out of bed, use the toilet, bathe, dress and eat, for example. Personal assistance services needed at the workplace might include assistance with eating lunch for someone with quadriplegia, or assistance with toileting for someone who uses a catheter bag. Personal care needs like these are generally not considered part of an employer’s responsibility to provide support services. People with disabilities who work are generally responsible for their own personal care needs at the workplace. These needs may be paid for by the individual or through insurance, including MaineCare.

Jack enjoyed working in his home office as an independent contractor, but was soon offered a permanent job with a local company. The job would mean a more stable income, a nicely furnished office downtown, and a chance to be more involved with work colleagues – these are all things he thinks he would enjoy. The company is even willing to be flexible about work hours. Jack would jump at the chance to go to work for this company, but he needs to make sure he can still use MaineCare personal care services during the day while he is at work.

Other types of work-related personal assistance could include transportation to and from work or learning independent living skills that contribute to success on the job.

A working person who uses personal assistance services during the workday may pay for services out-of-pocket, through a publicly funded program, or through some type of insurance. Some working people might have a private health insurance plan, perhaps through long-term

²⁸ Salley, S. T., & Glantz, L. (2002). *The MaineCare Option for Workers with Disabilities: A survey of past and present enrollees*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy.

²⁹ Vaughn, L., Evans, L., Gray, C. (2004) *Personal Assistance Services for Workers with Disabilities: Case Studies (2004)*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. <http://choices.muskie.usm.maine.edu/PAScasestudies.htm>

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disability coverage, that covers personal care and other assistance services. For many people with disabilities, however, MaineCare is the only source of insurance that pays for long-term support services such as PAS.

Relatively few working people with disabilities who are eligible for MaineCare use personal care services from a paid worker. In a 2003 CHOICES project survey of people enrolled in MaineCare through the Workers with Disabilities Option, 346 people were employed at the time of the survey. Of those, fourteen people (four percent) used personal care services from a paid worker. Three people (less than one percent), used personal care from a paid worker to get ready for work. Two people (less than one percent), used personal care from a paid worker at a worksite.³⁰

People are more likely to use personal care and other types of assistance from an unpaid person, such as a friend, family member, or coworker. Twenty-five percent (86 people) used some type of personal assistance service from an unpaid worker. One percent used personal assistance services from an unpaid worker at home to get ready for work (five people) or at work (four people).³¹

Most working people in the survey said they used PAS for tasks such as shopping, errands, meals and housekeeping. A smaller proportion of the group used other types of services such as help with making decisions, transportation, paying bills, and counseling or moral support. (Some of these services may not be covered by MaineCare.) The types of PAS received is similar, whether PAS is provided by a paid worker or unpaid person.³²

The Mental Retardation Waiver and Community Support Services for people with mental illness are MaineCare service packages that can provide services at the workplace. These services might include learning how to communicate with supervisors and co-workers, as well as assistance in building skills to persist at a task and work at a reasonable pace. In fiscal year 2003, more than 570 people ages 16 to 65 used supported employment services.

³⁰ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346.

³¹ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346.

³² Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy.

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Characteristics of Working People with Disabilities Who Use Personal Assistance Services

Among the 346 people with disabilities who were working at the time of the survey, four percent used paid personal assistance services.³³ Among this small group of individuals (fourteen people), the survey found that:

- ❖ A very large majority said they worked in jobs that are service or maintenance positions like cashier, dishwasher, or janitor.
- ❖ Most said they earned six to eight dollars an hour.
- ❖ The largest proportion were 35 to 54 years old.
- ❖ Physical disability and mental health disability (including substance abuse) were the two most common disability types reported.

With changes in MaineCare policies clarifying that personal care services can be used at his workplace, Jack is able to accept the job offer. Although arranging his personal care workers' schedules will always be challenging, Jack is relieved to know that his personal care needs won't hold him back in his career.

MaineCare Regulations Governing Where Services are Delivered

Personal assistance services provided through the MaineCare state plan and waiver service packages are generally delivered to people in their homes, where most people need assistance. In some service packages, MaineCare covers services delivered outside the home. As mentioned, the Mental Retardation Waiver covers personal support services provided in any setting, including the workplace. Community Support Services for people with mental illness may also be delivered in any location.

Private Duty Nursing, which provides services for people with physical disabilities, can in some cases be delivered outside the home “when required life activities take the member outside his or her residence (school, preschool, daycare, medical appointments, etc.).”³⁴ Personal Care Service regulations state that services can be provided in any location. This language will be incorporated into the policy manual this year (2004).

The policy manual governing MaineCare consumer directed options (which mostly serve people with physical disabilities) do not specify where services may or may not be delivered. However, the regulations for consumer-directed state plan services state that services can be provided in any location.

³³ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346.

³⁴ Chapter 2, Section 96 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s096.doc>>.

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Employers' Responsibility for Providing Personal Support Services at Work

Under the Americans with Disabilities Act (ADA, 1990), an employer is responsible for providing reasonable accommodations in the workplace to their employees.³⁵ These accommodations must be job-related and may include, among other things:³⁶

- ❖ Filing assistance
- ❖ Retrieving work materials that are out of reach
- ❖ Providing travel assistance for an employee with a mobility impairment
- ❖ Helping an employee with a cognitive disability with planning or decision making
- ❖ Reading handwritten mail to an employee with a visual impairment
- ❖ Ensuring a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment

Under the ADA, an employer's responsibility for personal assistance services in the workplace does not include skilled medical care.³⁷ Skilled medical care includes personal care assistance such as help with eating, toileting or dressing.³⁸ In addition, an employer's responsibility begins when the employee is at the job site and ends when the workday concludes.

Unmet and Anticipated Needs for Work-Related Personal Assistance Services

With regard to personal care services, as opposed to other types of personal assistance, survey findings suggest that work-related services play an important part in the lives of a relatively small number of people with disabilities. Less than one percent of workers with disabilities used paid personal care assistance at work or at home to get to work. Only a small percentage of working survey participants, an estimated three percent, reported that they needed but were not receiving personal care to get ready for work. An even smaller percentage said they needed but were not getting personal care services at the workplace.³⁹ In a similar survey of working people with disabilities, about one in four people using paid personal care services reported they did not have enough hours of services.⁴⁰

³⁵ Job Accommodations Network website, "ADA Questions and Answers". Reasonable accommodation is any modification or adjustment to a job or the work environment that will allow a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions. Reasonable accommodation also includes adjustments to assure that a qualified individual with a disability has rights and privileges in employment equal to those of employees without disabilities. For more information, go to <http://www.jan.wvu.edu/links/ADAq&a.html>.

³⁶ U.S. Department of Labor. Office of Disability Employment. *Personal Assistance Services in the Workplace*. Accessed Oct. 29, 2004
<<http://www.dol.gov/odep/pubs/ek97/personal.htm>>.

³⁷ U.S. Department of Labor. Office of Disability Employment. *Personal Assistance Services in the Workplace*. Accessed Oct. 29, 2004
<<http://www.dol.gov/odep/pubs/ek97/personal.htm>>.

³⁸ Silverstein, R.(2003). *Policy Brief: The Applicability of the ADA to Personal Assistance Services in the Workplace*. Center on State Systems and Employment; Institute for Community Inclusion; Center for the Study of and Advancement of Disability Policy. Issue 10; February.

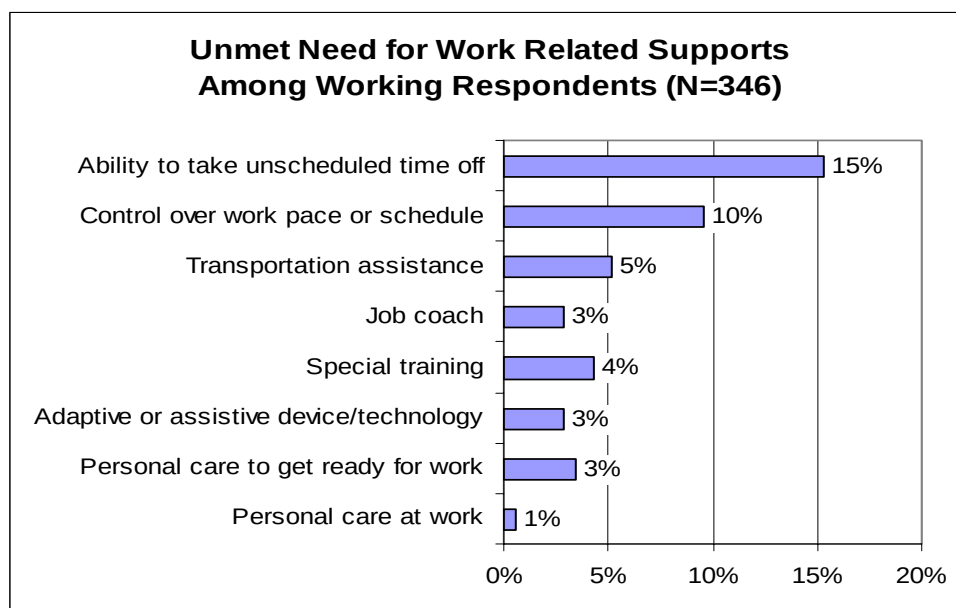
³⁹ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346

⁴⁰ Salley, S. T., & Glantz, L. (2002). *The MaineCare Option for Workers with Disabilities: A survey of past and present enrollees*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy, N=31.

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Of those not currently working, an estimated four percent anticipated that if they got a job they would need PAS at work, and nine percent anticipated needing PAS to get ready for work.⁴¹ Much larger percentages of people in the survey identified the need for other workplace supports and conditions to support their ability to work. The two working conditions they mentioned most often were control over their work pace or schedule and unscheduled time off.⁴² Employer flexibility around arrival times and changes in schedules is often necessary for a person with a disability to work. In addition, the amount of time needed to get ready for work and the availability of personal assistance at the right time are often important considerations.⁴³

Figure 1⁴⁴



⁴¹ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=194.

⁴² Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346

⁴³ Gray, C., & Glantz, L. (2003). *MaineCare and other supports for workers with disabilities: A summary report of focus group findings*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy.

⁴⁴ Anderson, N. & Mittal, P. (2005) *Working More, Earning More: Factors Associated with Employment Outcomes Among Enrollees in the MaineCare Option for Workers with Disabilities*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. N=346

MaineCare Personal Assistance Services in the Workplace

Conclusions and Next Steps

Gainful employment is an important personal goal for many people with disabilities, including people who need personal assistance services. The MaineCare Option for Workers with Disabilities and other MaineCare initiatives demonstrate that encouraging and supporting people to work is an important policy goal as well. A number of MaineCare enrollees use personal assistance services to get ready for work, and some of these individuals need PAS while they are actually at the job site.

However, there are several barriers to using personal assistance services to support work. Focus group⁴⁵ and case study participants⁴⁶ have noted the following challenges:

- ❖ Low pay scales along with high turnover/burnout rates for Personal Care Attendants (PCAs) make it difficult to find and keep good workers.
- ❖ Locating workers who can provide services in early morning hours is difficult – this is especially important for people who need to be at work early in the morning.
- ❖ Transportation to work is very important - some options do not allow PCAs to transport a consumer to recreational, educational or vocational settings.

Policy manual changes will soon ensure that MaineCare personal assistance services will be available outside a person's home, including in the workplace. Implementing this policy may have operational and fiscal implications that need further study. Some of the issues that could benefit from further research and analysis include:

- ❖ What are the extent and nature of personal assistance needs among working people?
- ❖ How many people who use personal assistance services are working or want to work?
- ❖ Do the personal assistance needs of working people differ from non-working people and if they do, in what ways are they different?
- ❖ How can workplace services be most effectively delivered?
- ❖ How should workplace personal assistance services be integrated with employer-provided accommodations?

In addition, the current Medical Eligibility Determination (MED) assessment tool for determining personal assistance needs does not record whether a person has a job and does not gather information pertaining to employment. Information about employment-related personal assistance needs collected through the assessment process could be helpful in answering some of these questions.

⁴⁵ Gray, C., & Glantz, L. (2003). *MaineCare and other supports for workers with disabilities: A summary report of focus group findings*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy.

⁴⁶ Vaughn, L., Evans, L., Gray, C. (2004) *Personal Assistance Services for Workers with Disabilities: Case Studies (2004)*. Portland, ME: University of Southern Maine, Muskie School of Public Service, Institute for Health Policy. <http://choices.muskie.usm.maine.edu/PAScasestudies.htm>

MaineCare Personal Assistance Services in the Workplace

Appendix A Service Package Description

Service Package Option	Description	Covered Services⁴⁷	Number Served Using PAS FY 2003 Ages 16-65⁴⁸
Physically Disabled Waiver (Consumer-Directed)	Allows eligible people to hire, train and supervise their own attendant to assist with a range of Activities of Daily Living, Instrumental Activities of Daily Living, and Health Maintenance Activities. ⁴⁹	Case Management with Skills Training and Consumer-Directed Personal Care Attendants	291
Consumer-Directed Attendant Services	Allows eligible people to hire, train and supervise their own attendant to assist with a range of Activities of Daily Living, Instrumental Activities of Daily Living, and Health Maintenance Activities. ⁵⁰	Case Management with Skills Training and Consumer-Directed Personal Care Attendants	254
Home Health	Provides “part-time” or “intermittent” services by a Medicare certified home health agency to a person in his/her home or other particular settings with limitations, according to the orders of a licensed physician and an authorized plan of care. ⁵¹	Nursing, Home Health Aide, Physical and Occupational Therapy, Social Work, Psychiatric Medication Visits	265

⁴⁷ Covered services may be dependant on eligibility criteria.

⁴⁸ Numbers are based on claims data for fiscal year 2003. People may be in more than one category of service.

⁴⁹ Chapter 2, Section 22 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s022.doc>>.

⁵⁰ Chapter 2, Section 12 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s012.doc>>.

⁵¹ Chapter 2, Section 40 MaineCare Benefits Manual. Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s040.doc>>.

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Service Package Option	Description	Covered Services ⁴⁷	Number Served Using PAS FY 2003 Ages 16-65 ⁴⁸
Private Duty Nursing /Personal Care Services	Provides services such as nursing and personal care services when determined to be medically necessary, has prior authorization, and is in the best interest of the member according to the orders and written plan of care reviewed and signed by a licensed physician. ⁵²	Nursing, Home Health Aide, Personal Care Attendant	539
Elderly and Adults with Disability Waiver	Provides in-home care and other services designed as a package to assist eligible people to remain in their homes, or other residential community settings, and thereby avoiding or delaying institutional nursing facility care. ⁵³	Case Management, Nursing, Home Health Aide, Personal Care Attendant, Physical, Occupational and Speech Therapy, Adult Day Health, Emergency Response, Transportation, Respite	475

⁵² Chapter 2, Section 96 MaineCare Benefits Manual Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s096.doc>>.

⁵³ Chapter 2, Section 19 MaineCare Benefits Manual Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s019.doc>>.

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Service Package Option	Description	Covered Services⁵⁴	Number Served Using PAS FY 2003 Ages 16-65⁵⁵
Mental Retardation Waiver	Allows eligible people with mental retardation to reside or continue to reside in the least restrictive setting by providing services such as habilitation, personal support services and supported employment. ⁵⁶	Habilitation, Consultation, Respite, Transportation, Adaptive Aids, Communication Aids, Interpreter, Crisis Intervention, Environmental Modifications, Personal Support Services, Supported Employment Services	1,371
Community Support Services	Provides services such as case management and community support to eligible people with severe and disabling mental illness who needs services that promote the integration into the community, sustain the person in his or her current living situation or another living situation of his or her choice, and enhance the quality of his or her life. ⁵⁷	Community Support Services, Interpreter, Case Management, Assertive Community Treatment, In-Home Support, Medication Services, Day Treatment/Rehabilitation Services	114

⁵⁴ Covered services may be dependant on eligibility criteria.

⁵⁵ Numbers are based on claims data for fiscal year 2003. People may be in more than one category of service.

⁵⁶ Chapter 2, Section 21 MaineCare Benefits Manual Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s021.doc>>.

⁵⁷ Chapter 2, Section 17 MaineCare Benefits Manual Accessed Oct. 29, 2004 <<ftp://ftp.state.me.us/pub/sos/cec/rcn/apa/10/144/ch101/c2s017.doc>>.

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Appendix B Service Package Administration

Service Package Option	Overseeing Administration	Administrator	Assessment	Funding Source
Physically Disabled Waiver (Consumer-Directed)	Department of Health and Human Services (DHHS): Bureau of Elder and Adult Services (BEAS)	Alpha One	Goold	MaineCare
Consumer-Directed Attendant Services	DHHS: BEAS	Alpha One	Goold	MaineCare
Home Health	DHHS: BEAS	Medicare Certified Home Health Agency	Goold	MaineCare
Private Duty Nursing/PCS	DHHS: BEAS	Elder Independence of Maine (EIM)	Goold	MaineCare
Elderly and Adults with Disability Waiver	DHHS: BEAS	EIM	Goold	MaineCare
Mental Retardation Waiver	DHHS: Behavioral and Developmental Services (BDS)	DHHS: BDS	DHHS: BDS	MaineCare
Community Support Services	DHHS: BDS	Community Support Provider	DHHS: BDS /Community Support Provider	MaineCare

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Appendix C For More Information

MaineCare

<http://www.state.me.us/dhhs/bfi/MaineCare.htm>

Department of Health and Human Services (DHHS): Bureau of Elder and Adult Services (BEAS)

<http://www.state.me.us/dhhs/beas/welcome.htm>

DHHS: Behavioral and Developmental Services (BDS)

<http://www.state.me.us/bds>

Elder Independence of Maine (EIM)

<http://www.elderindependence.org>

Alpha One

<http://www.alphaonenow.com>

Bureau of Rehabilitation Services (BRS)

<http://www.state.me.us/rehab>

CHOICES Project

<http://choices.muskie.usm.maine.edu>

MaineCare Personal Assistance Services in the Workplace

Appendix D Procedure Codes that Identify Personal Assistance Services

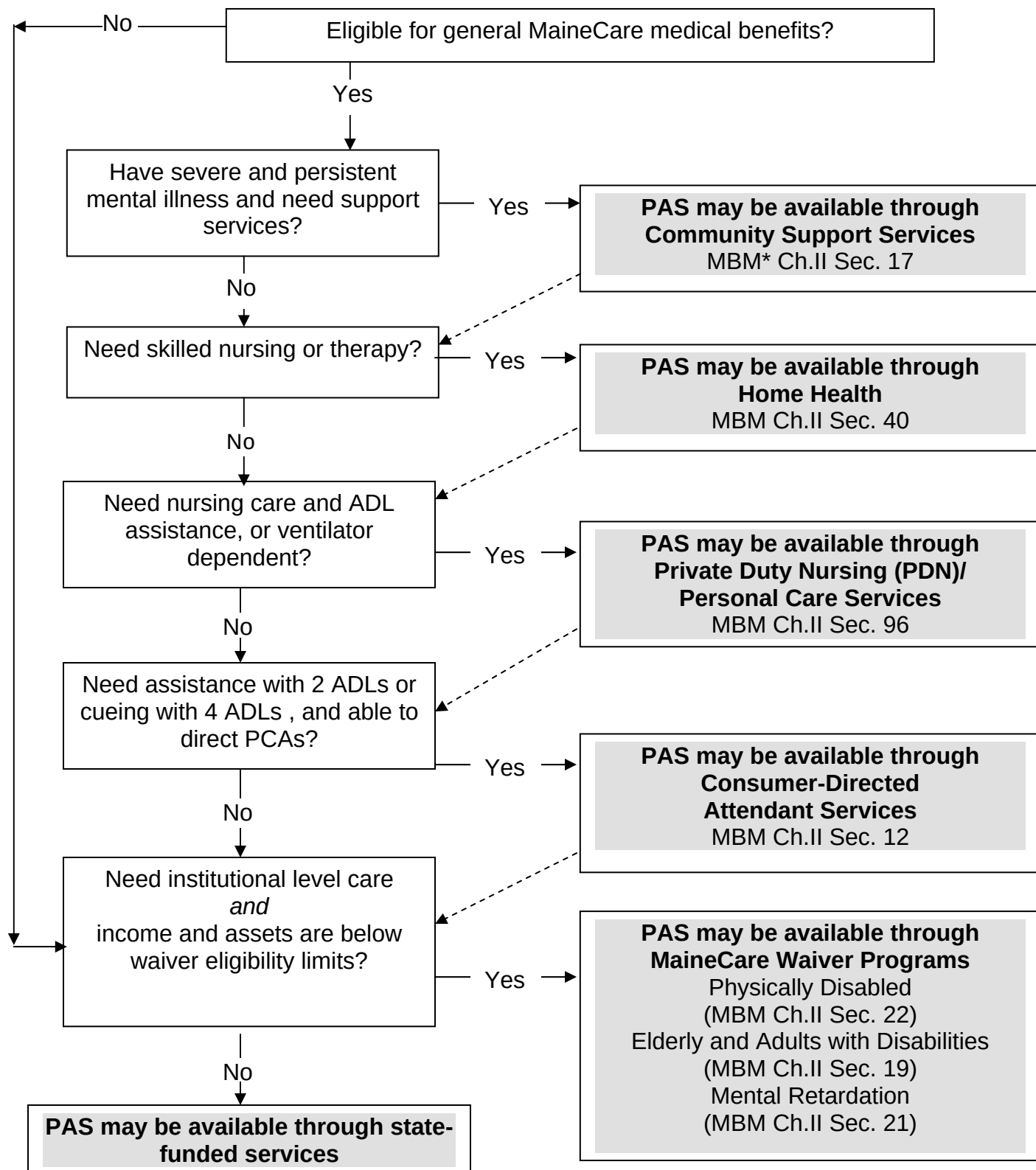
MaineCare Service Category	Procedure Code	Description
Private Duty Nursing/ Personal Care Services	B108	HHA services, at risk under 21, 30 min
	B109	CNA services, at risk under 21, 30 min
	B113	HHA services, NF under 21, 30 min
	B114	CNA services, NF under 21, 30 min.
	B118	HHA services, ext under 21, 30 min
	B119	CNA services, ext under 21, 30 min
	B123	HHA Services per 1/2 hour
	B124	CNA Services per 1/2 hour
	B125	PCA Services per 1/2 hour
	B128	HHA services, at risk and over, 30 min
	B129	CNA services, at risk and over, 30 min
	B135	PCA services persons age 21+ ext
	B138	HHA Services per 1/2 hour
	B139	CNA services, ext 21+, 30 min
	B361	PCA per ½ hour
	B362	PCA Services per 1/2 hour
	B363	PCA per ½ hour
	B364	PCA Services per 1/2 hour
Home Health	B103	CNA Services
	B113	HHA services, NF under 21, 30 min
	HHS13	HHA Services

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Elderly and Adults with Disabilities Waiver	EW03	PCA Services per 1/2 hour (EW)
	EW14	Waivered HHA Services – CNA per ½ hour (EW)
	EW33	Waivered HHA Services – HHA visit per report (EW)
	EW37 HC3	Waivered HHA Services – HHA per ½ hour (EW) PCA Services per 1/2 hour (ADW)
	HC17	Waivered HHA Services – CNA per ½ hour (ADW)
	HC18	Waivered HHA Services – HHA per ½ hour (ADW)
	HC26	Waivered HHA Services – HHA visit per report(ADW)
Physically Disabled Waiver (Consumer-Directed)	C004	PCA (HR allowance during awake hours)
Consumer-Directed Attendant Services	CA22	PCA 1 hour
	CA25	PCA ½ hour
Mental Retardation Waiver	W125	Personal Support Services – per hour
	W126	Supported Employment Services – per hour
Community Support Services	H2014	Skills Development Services – per 15 min
	H2015	Community Integration Services – per 15 min
	H2017	Daily Living Support Services – per 15 min
	H2025	Skills Development Services/Training – per 15 min

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Appendix E MaineCare Eligibility Flow Chart



This document is also available on the Internet, at
<http://choices.muskie.usm.maine.edu/PASreport.htm>

Available in alternative formats upon request.

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- New England Environmental Finance Center
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