Access Choice and Control: A Comparative Analysis of Maine's Personal Assistance Services Programs

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Access, Choice and Control
A Comparative Analysis of Maine's Personal Assistance Services Programs

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In spite of the many contributions to this document, the views represented here are entirely those of the author and do not necessarily represent the views of the Maine Department of Health and Human Services, the federal Centers for Medicare and Medicaid Services, or any of those who have provided input or information.
Summary

The purpose of this analysis was to identify opportunities for eliminating unnecessary inconsistency and increasing consumer choice and control across Maine’s personal assistance services (PAS) programs. A comparative analysis of Maine’s PAS programs reveals that:

- Maine PAS programs vary in the level of support they offer but the difference in support cannot necessarily be explained by differences in the level of need. It is anticipated that tension around these inconsistencies (and inequities) will be heightened by the Department’s reorganization, which brings almost all PAS programs together under one roof, and the current budget crisis, which fuels competition for resources.

- Maine PAS programs have been and are currently working toward increasing opportunities for expanding consumer choice and control over services. However, there continues to be significant potential for increasing consumer ownership of services. While budget constraints might the State’s ability to expand services, they do not necessarily limit the State’s ability to improve consumer choice and control over services.

To address these findings, the following recommendations are made:

1. Develop common goal for allocating PAS. To promote equity across programs, the State should define a shared goal for its PAS programs. Developing consensus on how to apply that goal across population and age groups would be challenging. At the same time, the State faces an ongoing struggle, internally and externally, to justify or challenge the existing allocation of resources. Without a standard for evaluating program goals and the allocation of resources, these battles are often won based on political might rather than rational decision making.

2. Develop comparable measures of need across PAS programs. While a clinical diagnosis may be important to determining how to meet a need, diagnosis should not determine how resources are allocated. Defining a comparable measure of need across population groups would enable the State to work toward equitably distributing resources across groups, consistent with its common goal.

3. Develop budgets with an independent assessor using a standardized tool and process for determining level of need. The “gatekeeping” function – the allocation of resources across competing needs – is a core government function. The independent assessor is a tool for ensuring that the gatekeeping function is done rationally and equitably. Attacks on the gatekeeping function are better directed at the criteria for allocating resources, the level of resources available to be allocated, and the training and consistency of those doing the allocation.
4. Develop consistent worker credentials and pay scales across programs. Developing consistent criteria for credentialing and paying workers would enable more equitable access to workers across programs.

5. Expand supportive and substitute decision making options. Allow individuals with impaired decision making capacity to seek assistance from others for directing services.

6. Give consumers the right to choose among a range of permitted uses for PAS budgets. A consumer should be able to use PAS funds to purchase alternative services, goods, and equipment when a substitution would increase the efficiency or effectiveness of PAS.

7. Expand to all population groups the option to select and manage direct support workers. With supported or substitute decision making options available, consumer direction of workers should be available across programs.

8. Maximize flexibility in the service plan. In developing the service plan, the consumer should be able to decide whether or not to use personal assistance on the jobsite or another setting and whether to pay a job coach, a co-worker, or a friend to provide personal assistance in these different settings.

9. Develop a conflict-free service broker option to support consumer control over service planning and evaluation. The service broker would provide a service coordination function, assisting an individual with developing a service plan and periodically monitoring and evaluating the effectiveness of the service plan.

10. Expand consumer role in the design of services and the evaluation of service quality. Consumers can play a valuable role in identifying opportunities for improving services.

11. Provide a range of service models offering consumers choice over how much control to exercise. Some individuals will need no help finding and scheduling workers. Others will not feel comfortable in that role. Some individuals will have family and friends in close proximity to provide emergency back-up, while others will not have a natural support system. To satisfy the individual needs of different consumers, a flexible array of service options would allow consumers to select the level of support best for them.

12. Minimize the need to choose among PAS programs by increasing flexibility within programs and coordination across programs. More flexibility and better coordination would mean consumers would not have to make an “either/or” choice of which needs will be met in a specialized program.

13. Support meaningful choice among workers by paying competitive wage rates and benefits. While not losing sight of other factors impacting worker availability, the State should continue its efforts to increase worker pay and access to health benefits.
Background

In January 2000, the Maine Department of Health and Human Services (DHHS) convened a Steering Committee to develop Maine’s response to the Olmstead decision. The Olmstead decision is a U.S. Supreme Court decision requiring states to provide services to persons with disabilities in the most integrated setting appropriate to their needs. The Steering Committee, in turn, convened the Work Group for Community-Based Living, a group comprising state staff and consumer representatives, to develop recommendations in response to the Olmstead decision. As an extension of this effort, in 2001, the Work Group collaborated in the development of the Quality Choices for Maine grant proposal under the federal government’s New Freedom Initiative. Through DHHS the Work Group proposed twelve different project activities under Quality Choices. One of the proposed activities was to conduct a policy review of personal assistance services offered in Maine across programs, departments and population groups served. The purpose of this review would be to identify unnecessary inconsistencies in personal assistance services (PAS) policy, and opportunities for increasing consumer choice and control over personal assistance services.

The Work Group has served as the Consumer Taskforce for the Quality Choices of Maine grant activities. The Person Centered Services Technical Advisory Group provided regular guidance and direction for this report.

This policy review was conducted by reviewing written policy for a number of direct support services.¹ Over the course of this project, many of these policies were revised once, some two or three times. Initially an attempt was made to review policy changes and update the policy review contained in this report. However, the most recent round of policy changes has not been systematically reviewed and incorporated into this policy analysis. The narrative references some of these changes, anticipated or recently made.

Maine’s PAS programs have also changed organizationally over the course of this project. In 2002, the consumer directed PAS programs (Medicaid state plan, Medicaid waiver and state-funded) were transferred from the Bureau of Elder and Adult Services (BEAS), within DHHS, to the Bureau of Rehabilitation Services (BRS) within the Department of Labor. In 2004, the Medicaid consumer-directed programs were transferred back to DHHS. Also in 2004, the former Department of Human Services and the Department of Behavioral and Developmental Services were merged to become the Department of Health and Human Services, bringing almost all PAS programs within one department.

The product of this analysis is a series of recommendations for eliminating unnecessary inconsistency, and increasing consumer choice and control across PAS programs. Many of these recommendations anticipate changes already under way. In fact, since this project began the State has taken a number of steps to improve consumer choice and control over PAS:

¹ See APPENDIX for a list of the policies reviewed for this report.
• Under the Quality Choices grant, Maine has developed a Fiscal/Employer Agent (FEA) model (also known as “fiscal management services”) to support consumer directed PAS. The FEA will be implemented in both the elder and adult programs and under a new self-directed waiver for persons with mental retardation.

• The PAS program for elders, adults and children, funded under the Medicaid state plan is being amended to offer a family provider service option, allowing individuals or family members to direct PAS as surrogates.

• DHHS has acquired two more grants under the New Freedom Initiative. The Money Follows the Person grant will develop a standardized rate and budget allocation tool for MR Services, enabling greater consistency in the allocation of resources within that program. The individualized budgeting tools developed under this grant will support the self-directed waiver being developed under DHHS’ Independence Plus grant.

• DHHS also received a Quality Assurance/Quality Improvement grant under the New Freedom Initiative to fund improvements in waiver programs. Some of these funds are being used to refine a participation experience survey for use with self-directed services and to fund consumer participation in defining and measuring quality.

• The Legislature required the Department of Health and Human Services and the Department of Labor to establish rules governing consumer directed programs that affirm the principles of consumer direction, provide for the independent assessment and reassessment of eligibility and service need, and authorize services based on functional need, consistent with appropriations and law. The two departments were required to form a study group to review and report back to the Legislature with recommendations on the guiding principles for expanding eligibility for consumer direction to persons who use a surrogate decision maker.

While much progress has already been made, this report identifies more opportunity for minimizing inconsistent access to services and expanding consumer choice and control. In the context of current budget shortfalls, the State’s ability to expand access to PAS is limited. However, budget limitations do not need to end progress toward enhanced consumer choice and control over PAS and provide all the more incentive to evaluate the equitable allocation of access. This document is meant to provide a framework for the State’s continued efforts.
In the ideal, personal assistance puts an individual with a disability on a level playing field with persons who do not have a disability by compensating for the disability:

Personal assistance enables users to take their rightful place in family, at work and society with all the rights and duties that the general population takes for granted. With personal assistance persons with extensive disabilities need no longer be a burden on their families. Parents, husbands or wives do not need to stay at home and sacrifice their careers. Personal assistance users not only manage on their own, they can also take their share of household and child-rearing. With personal assistance we can attend school and educate ourselves, enter the labour market and become tax-payers. When we fall in love, our partners need not fear that they are about to sign up for a life-long 24 hour job.²

To reflect this ideal, the scope of this review was defined to include any service that compensates for a disability by delegating to another individual a task which a person with a disability would perform him or herself, but for the disability. For the purposes of this review, three main categories of PAS programs were identified as falling into this definition:³

**Agency-Based Personal Assistance Programs.** The elder and adult programs provide a variety of types of PAS (e.g., personal assistance, homemaker, chore services) to elders and adults meeting functional or medical eligibility criteria. Most services are available through agencies, although some of these programs now offer the option for the consumer or a surrogate to direct services. Also, included in this category are Medicaid funded personal assistance services for children. The PAS programs falling into this category include:

- Personal assistance services for adults and elders:
  - Private duty nursing/personal care services (Medicaid state plan)
  - Elder/adult waiver services (Medicaid waiver services)
  - Home based care (state funded)
- Homemaker services for adults and elders (state funded)

This category of services are all administered by the Bureau of Elder and Adult Services (BEAS), within the Department of Health and Human Services (DHHS).

**Consumer-Directed Personal Assistance Programs.** For persons meeting the functional or medical eligibility criteria and able to self-direct, these services also address a person’s functional need for physical and medical assistance with self-care and activities

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³ See APPENDIX for an inventory of the policies reviewed for this report.
instrumental to self-care. The consumer-directed programs serve adults, although there are elders on the program. The PAS programs falling into this category include:

- Consumer-directed personal assistance (Medicaid state plan, administered by BEAS)
- Adults with physical disability waiver (Medicaid waiver services, administered by BEAS)
- Consumer-directed home based care (state funded, administered by the Bureau of Rehabilitation Services (BRS), within the Department of Labor)

Personal Supports/MR Waiver. The Home and Community Based Waiver for Persons with Mental Retardation (“the MR waiver”) offers personal support services. Personal support services can include the physical and medical assistance associated with personal assistance programs. However, personal supports include non-physical assistance, including assistance with judgment, supervision or monitoring, and a habilitative component including guiding, modeling, and coaching an individual in performing activities for him or herself. The MR waiver is administered by Adult Mental Retardation Services (“MR Services”).

Excluded from this definition are services that might include some personal assistance but are intended to be predominantly instructional, focusing on developing daily living skills, rather than assisting with daily living activities (e.g., habilitation or behavioral services for children). Daily living supports for adults with mental illness fell on the margin as a personal assistance service. This service provides “supervision and therapeutic support” to assist individuals with developing and maintaining daily living skills. Support methods include cueing, modeling, and coaching. Also excluded from this review are any personal assistance services tied to a residential setting, such as assisted living or residential training services.

While technically falling into the definition of “personal assistance,” some services were omitted from review here, because they were targeted for a specific use of limited value to the analysis. These services include home health aide services provided under Medicaid home health services; job supports provided under the home and community-based waiver for persons with mental retardation; personal assistance available under Medicaid-funded Prevention, Health Promotion, and Optional Treatment Services (formerly Early and Periodic Screening, Diagnosis, and Treatment Services); job supports and personal assistance services offered through the vocational rehabilitation program.

For many of the services excluded from review here, it is very possible that much of the analysis and recommendations still apply. The concepts of inconsistent access, and choice and control can apply to different types of services and services provided in different contexts.

For those PAS policies within the scope of this analysis, in addition to reviewing written policies, interviews of key staff were also conducted. See the POLICY REVIEW SUMMARY MATRIX at the end of this section for background information on these programs.
Eligibility Criteria
The different programs use a variety of criteria for defining the population group eligible for a particular personal assistance service. These criteria might include:

- the type of disability a person has
- a measure of functional need for services
- the severity of a person’s disability
- age
- income

Other criteria may also apply. For example, some PAS programs condition eligibility on where a person resides; consumer directed programs might be limited to those persons with the ability to direct their own services.

Type of Disability. By statute, several program areas are defined by type of disability. Within the scope of this review, MR Services is authorized to serve persons with mental retardation or autism. Because eligibility is statutorily tied to a type of disability, MR Services necessarily includes type of disability as one basis for determining eligibility for the personal assistance services they offer. Thus, to be eligible for the MR waiver, an adult must have a clinical determination that he or she has mental retardation or autism.

Functional Eligibility Criteria. Functional eligibility criteria measure a person’s need for services as a basis for determining eligibility for services. Thus, for some programs, eligibility is based on an individual’s need for assistance with “activities of daily living” and “instrumental activities of daily living.” For these programs, activities of daily living (ADLs) are generally defined to include basic self-care activities such as eating, bathing, grooming, dressing, and toileting. “Instrumental activities of daily living” (IADLs) include other activities instrumental to basic self-care, such as cooking, cleaning, shopping, etc. The eligibility criteria for personal assistance services and homemaker services use a person’s need for assistance with ADLs and IADLs as a basis for determining eligibility. The eligibility criteria are often intricate, with different levels of service associated with different levels of functional need.

In addition to measuring need for assistance, eligibility is based on the type of assistance required. For example, eligibility for personal assistance services under MaineCare’s Private Duty Nursing distinguishes between the need for several types of assistance:

- **Cueing.** Spoken instruction or physical guidance serving as a signal to do something.
- **Limited assistance.** Guided maneuvering of limbs or other non-weight-bearing assistance.

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4 34-B MRSA Chapter 5 & 6.
5 By statute, “mental retardation” is defined to mean significantly subaverage intellectual functioning resulting in or associated with concurrent impairments in adaptive behavior and manifested during the developmental period. 34-B MRSA § 5001. By statute, “autism” refers to a developmental disorder characterized by a lack of responsiveness to other people, gross impairment in communicative skills and unusual responses to various aspects of the environment, all usually developing within the first 30 months of age. 34-B MRSA § 6002.
• **One person physical assist.** Weight-bearing or non-weight-bearing assistance for an individual who cannot perform the activity independently.

• **Extensive assistance.** Weight-bearing support or full caregiver performance at least part of the time.

• **Total dependence.** Full caregiver performance all of the time.

In some cases, eligibility will also depend on an individual’s need for nursing services and other services, which are provided in addition to the personal assistance services. For adults and elders requiring cueing but no physical assistance, the level of service is limited. For MR Services, eligibility is not conditioned on the need for physical assistance. The need for monitoring or guidance in the performance of an activity is sufficient basis for eligibility.

**Severity of Disability.** Some programs use the “severity” of a disability as a threshold for eligibility. Functional, medical and other criteria are used to measure severity.

Under federal law, eligibility for a Home and Community-Based Services (HCBS) waiver is based on a determination that the individual’s disability requires nursing facility level care. Thus, to be eligible for HCBS waiver services, an individual must be eligible for admission to a nursing facility or ICF-MR. It is worth noting that the threshold for requiring nursing facility level of service is much more rigorous than that for ICF-MRs. A person meets the medical eligibility requirements for NF services if he or she:

• Needs at least one skilled nursing service 7 days per week; or

• Needs at least one skilled nursing service at least 3 days per week in addition to two other services (any combination of skilled nursing service three days per week or "limited assistance" and a "one person physical assist" needed with bed mobility, transfer, locomotion, eating or toilet use); or

• Meets a qualifying score on a cognition and behavioral screen or needs at least limited assistance with bed mobility, transfer, locomotion, eating and toilet use for a total of three service needs.

By setting the standard for admission to a nursing facility relatively high, the State has been able to significantly reduce reliance on nursing facility services. However, because of the federal limitation of waiver services to only persons who might otherwise be served in a nursing facility, the NF eligibility requirements necessarily limit eligibility for waiver services.

In contrast, an individual is eligible for an ICF-MR, if he or she satisfies any combination of the following:

• Independent in mobility or in the use of a wheelchair or other mobility device.

• May need assistance in personal care such as oral hygiene, care of skin, personal grooming and bathing.

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6 Under MaineCare Benefits Manual, Chapter II, Section 50, ICF-MR Services, there are two levels of eligibility for ICF-MR services, ICF-MR nursing services and ICF-MR group home facility services. The lower eligibility threshold (group home) is used to determine eligibility for waiver services.
• May exhibit or has exhibited deviation from acceptable behavior.
• May require some personal supervision.
• May require some protection from environmental hazards.
• Is able to participate, under supervision, in diversional and motivational activities both in
  the facility and in the community.
• Is able to participate in one or more developmental, vocational, or community programs.
• Medications ordered by the physician are of a routine nature that can be administered by
  qualified group home facility personnel.
• May be aphasic.7

The relatively loose eligibility requirements for ICF-MRs allow MR Services to apply looser
eligibility criteria for the MR waiver.

Age. A number of personal assistance service programs target adults only. There are no
personal assistance service programs targeted specifically to children. Only personal assistance
provided under the Medicaid state plan service, Private Duty Nursing/Personal Care Services,
and personal support services under the MR Waiver are not limited to adults.8

Under Private Duty Nursing, there are five levels of care that offer personal assistance services.
One level, Level IV, is limited to children under age 21 who are eligible for admission to a
nursing facility but who want to receive services at home. If a child does not meet the eligibility
criteria under Private Duty Nursing, he or she can be reviewed for eligibility under the
Prevention, Health Promotion, and Optional Treatment Services (PHPOT), formerly known as
Early and Periodic Screening, Diagnosis and Treatment Services (EPSDT). If PAS is
determined to be medically necessary under PHPOT, the child can receive Private Duty
Nursing/Personal Care Services.

The availability of PAS varies by age group at least partially because the needs of children are
different from the needs of adults. For the purpose of this policy review, PAS has been viewed
as a tool for achieving independence, compensating for an individual’s disability by performing
tasks the individual is unable to perform because of his or her disability. Children, with or
without a disability, are not expected to care for themselves without some level of adult care or
supervision. Instead, much of childhood is spent learning the skills for attaining independence in
adulthood. As a result, rather than performing activities of daily living on the child’s behalf, a
number of children’s services focus on developing daily living skills in order to maximize the
child’s ability to live independently. For example, many children with mental retardation receive
day habilitation, which focuses on instructional services, teaching and maintaining skills of daily
living.9 Similarly, behavioral health services are also habilitative, focusing on behavior
management and skills development.10

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7 MaineCare Benefits Manual, Chapter II, Section 50.05(A).
8 The Department of Health and Human Services has plans to develop a waiver for children with mental retardation
  and autism, separating children’s services out of the existing MR waiver.
9 MaineCare Benefits Manual, Chapter II, Section 24.
10 MaineCare Benefits Manual, Chapter II, Section 65.
**Income and Assets.** Income eligibility for PAS depends on the funding stream, and the availability of PAS by funding stream varies by population group. TABLE 1 identifies PAS programs by funding stream and population group. See the POLICY REVIEW SUMMARY MATRIX at the end of this section, for income and asset eligibility criteria by program. Income and asset thresholds tend to be more generous for children. For example, under the “Katie Beckett” eligibility category, for children who are eligible for nursing facility level of care, only the child’s income and assets, not the parents’, are counted. Services funded under the general fund have only recently applied financial eligibility criteria.

While income and asset thresholds serve to target resources to those with the most financial need, the risk of losing benefits means historically many people with disabilities have had to choose between keeping the services they need or working. The MaineCare Workers with Disabilities Option attempts to remedy this dilemma. Under the Workers with Disabilities Option, a person can earn money and retain MaineCare eligibility up to a certain income threshold.

**TABLE 1. The Availability of PAS by Funding Stream and Population Group**

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th>Adults with mental retardation and autism</th>
<th>Adults with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>MaineCare State Plan Services</td>
<td>Private duty nursing/personal care services</td>
<td>NA</td>
<td>Private duty nursing/personal care services Consumer- Directed PAS</td>
</tr>
<tr>
<td>MaineCare HCBS Waiver</td>
<td>MR waiver</td>
<td>MR waiver</td>
<td>Elder &amp; Adult waiver Consumer-Directed PAS waiver</td>
</tr>
<tr>
<td>State funded</td>
<td>NA</td>
<td>NA</td>
<td>Home Based Care Home Based Care Consumer-Directed PAS Homemaker services</td>
</tr>
</tbody>
</table>

**Scope of Personal Assistance Services**

For the purposes of this review, the scope of service is defined by the services for which reimbursement is permitted by the administering program. Different types of personal assistance services provide different kinds of assistance with different tasks. Primarily the scope of services reimbursable as PAS can include these components:

*Assistance with Activities of Daily Living.* All personal assistance programs reimburse for assistance with activities of daily living. ADLs include a range of activities, including bed mobility, transfer, locomotion, eating, toileting, bathing, dressing, hygiene. With the exception of homemaker services, the scope of ADL services across personal assistance...
services is generally consistent and includes assistance with the full range of activities. Homemaker services include assistance with dressing and hygiene, when incidental to homemaking services.

*Assistance with Instrumental Activities of Daily Living.* IADLs include grocery shopping, errand, housework, chores, laundry, meal preparation, money management, transportation, etc. Relative to ADLs, Maine PAS programs have greater variation in the scope of IADLs covered. For example, the consumer directed programs cover “money management” and the agency-based services for elders and adults do not. Some types of personal assistance cover “chore” services (occasional heavy duty cleaning, changing storm windows, snow shoveling, etc.) and others do not. The scope of transportation services also varies across programs. Transportation is provided to elders and adults when necessary to access a covered Medicaid service. Transportation is provided to persons receiving MR waiver services when it is necessary to meet a stated goal in an individual’s service plan. Under MaineCare state plan services, personal assistance with IADLs is not available for children; it is assumed that parents have a responsibility for assistance with IADLs.

*Assistance with Health Maintenance Activities.* Health maintenance activities may include catheterization, ostomy care, preparation of food and tube feedings, bowel treatments, administration of medications, care of skin with damaged integrity, occupational and physical therapy activities such as assistance with prescribed exercise regimes. Health maintenance activities are available as part of personal assistance for self-directed services and for other programs serving elders and adults. While health maintenance activities may be reimbursable as a personal support service for a person with mental retardation, this category of service is not typically provided through this mechanism.

The availability of health maintenance services may depend on the type of personal assistant. While home health aides (HHAs) and certified nursing assistants (CNAs) have more formal training requirements than personal support specialists, their certification regulations limit their permitted scope of service. Other types of personal assistants, with less formal certification requirements, are not subject to the same limitations.

*Monitoring and Supervision.* For personal support services for persons with mental retardation the scope of service includes the presence of an individual to “supervise” and monitor the individual. While assistance with ADLs compensates where a disability impairs the ability to perform a physical task, the “supervisory” role might compensate where a disability impairs judgment. Monitoring might be necessary when an individual has a medical condition that requires prompt attention.

*Skill Acquisition and Retention.* Personal support services for persons with mental retardation include a teaching or modeling component to build an individual’s capacity for self-care, similar to the habilitative service excluded from this analysis.

Some PAS services are limited by the setting in which they can be provided. Under the MR waiver, personal support services provided on the job site are reimbursable. The same policy does not apply to personal assistance provided to elders and adults under other programs.
**Budget Caps**

Different programs have different limitations on the amount of PAS available.

*Budget cap depending on level of need.* Most service caps are based on an analysis of the level of impairment and utilization, with an attempt to make sure that budget caps are consistent across programs. The services provided to elders and adults have caps for different levels of need.

*Budget cap as a function of cost neutrality.* For both HCBS waiver services and services provided to persons eligible under the Katie Beckett eligibility category, federal Medicaid regulations require that the cost of home and community-based services be “cost-neutral” relative to what it would cost to provide services in an institutional setting. For the elder and adult waiver services, the individual’s service plan must cost less than or equal to the average annual cost of the nursing facility services ($52,092). For the consumer-directed PAS waiver services (the physically disabled waiver) the cap is the same, having been recently increased from 90% to 100% of nursing facility costs.

*No individual cap.* For the MR waiver, cost neutrality is measured on the group level so that all MR waiver services, on average, cannot exceed the average cost of serving a person in an ICF-MR ($116,000/year). Because the MR waiver measures cost neutrality across all persons it serves, there is no individual cap on MR waiver services.

See the **POLICY REVIEW SUMMARY MATRIX** at the end of this section for a listing of budget caps across PAS programs.

**Eligibility Determination and Service Plans**

Different programs have different approaches for determining eligibility, assessing an individual’s needs, and developing individual service plans:

*Elder and Adult Programs.* For the elder and adult programs, the eligibility determination and budget development are performed by an independent “assessing services agency,” not the providers who will deliver the services. A person applying for services is assessed by the “assessing services agency” for all elder and adult programs. The assessing services agency, Goold Health Systems, uses a standardized assessment tool, the Medical Eligibility Determination (MED) form, to determine eligibility. Based on the assessment of need, a service plan is developed. Elder Independence of Maine (EIM) is the home care coordinating agency responsible for assisting with implementation of the service plan, working with a multidisciplinary team to implement the service plan. EIM contracts with individual home health agencies to provide in home supports.

*Consumer-Directed Programs.* Until recently, for the consumer directed programs, the eligibility and budget development are performed by Alpha One, also using the MED.11 Once the budget and service plan are developed, Alpha One also served as the home care

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11 Under legislation transferring the consumer directed programs back to BEAS, the Legislature required the assessment to be conducted by an independent assessor.
coordinating agency and assists with implementation of the authorized personal assistance services, providing training and employer support services. Under recent policy changes, the assessment is now conducted by Goold Health Systems, with Alpha One serving as the home care coordinating agency.

**Adult MR Services.** A private clinician determines whether an individual has a diagnosis of mental retardation or autism. An Individual Service Coordinator (ISC) working in a DHHS regional office, works with an individual consumer to identify who should be part of the person centered planning process and what topics will be addressed by the planning team. The planning team may include the consumer, the Individual Support Coordinator, a parent or guardian, providers, and others. MR Services does not currently use a standardized budgeting tool. An individual’s needs are determined through the planning process and the planning team develops a service plan based on those needs. Following this process, a provider will submit a BMS-99 form that is used, in combination with the clinical diagnosis of mental retardation or autism, to determine eligibility for MR waiver services. MR Services and the provider negotiate the terms of the budget for providing the services under each individual plan. A “waiver checklist” is completed to record the authorized individual service plan.

**Katie Beckett Eligibility Category.** The MED, designed for elders and adults, has been used to determine whether children were eligible for nursing facility level of services (and thus eligible under the Katie Beckett eligibility category). DHHS has been working to modify the MED to specifically measure eligibility for children. Like the adult programs, the assessment is done by an independent assessing agency and the MED is used to determine eligibility. However, unlike the adult programs, the MED is not used to determine level of service (or a budget) and does not define a service package. Once eligible, the child’s service plan is developed with the provider.

**Worker Qualifications**

Required direct care worker qualifications vary across programs:

- Certified nursing assistants (CNAs) providing services to elders and adults must have 150 hours of training, meeting certification standards set by the Board of Nursing. The worker must also be listed on CNA registry.

- Home health aides (HHAs) have the same certification requirements and must also be listed on the CNA registry. In addition, the HHA must have an orientation provided by the home health agency.

- Personal support specialists serving elders and adults must have 40 hours of training, with the curriculum set by BEAS.

- Consumer-directed personal assistants are trained by the consumers they serve. The consumers also certify the assistant’s competency.
Personal support providers providing services to persons with mental retardation are qualified if they can demonstrate their competency to the Department.

This policy review did not include an analysis of the different training curricula or criteria for certification.

Reimbursement Rates and Pay Rates for PAS
The rate the State pays for PAS varies by the type of PAS, the program, and sometimes by who is providing the PAS services. The reimbursement rate is established using different methods:

**Consumer-Directed PAS.** Until recently, for the CD-PAS programs administered by Alpha One, the amount the State paid for PAS was set by contract with Alpha One. The reimbursement rate has blended the hourly rate for the service with Alpha One’s payment for administering the service. Pursuant to legislation transferring the Medicaid state plan and Medicaid waiver consumer-directed programs back to DHHS, the level of need for PAS will be determined by an independent assessor for these and the state funded consumer-directed program. The hourly rate for PAS will no longer be blended with the administrative cost.

**Other Elder and Adult Personal Assistance Services.** For personal assistance services provided under the Medicaid state plan, the elder and adult waiver, and the state funded home based care and homemaker programs, the amount the State pays for personal assistance services is set by regulation. The reimbursement rate is paid directly to the provider and includes home health agency overhead costs. (EIM receives a separate fee for providing home care coordinating agency services.)

**Personal Support Services.** The amount the State pays for personal support is negotiated for each service plan, based on the provider’s cost for providing the services.

The amount the State pays for services will differ from the amount a direct care worker receives depending on what other costs are to be covered by the reimbursement rate (e.g., a provider’s overhead costs, Alpha One’s employer support services). Although the State might know how much it pays for services, in most cases the State does not have accurate information about how much workers receive for services. Typically, the pay rate for direct care workers is set by the agency that employs them. (An exception: the payment rate for personal assistants hired through the consumer-directed PAS programs is set by the State’s contract with Alpha One.)

It is difficult to compare the reimbursement rate across programs because the rates include different costs. In addition, it is difficult to compare the rate of pay across workers because the information is based on estimates. Pay rates for direct support professionals under the MR waiver are estimates by MR staff (estimated to range from $8.50 to $12.00/hour). Estimates of pay for home health aides, certified nursing assistants, and personal care attendants employed by agencies are based on the 2001 median wage (estimated to range from $8.28 to $9.35/hour).

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12 These rates are taken from Lisa Pollman, *Without Care: Maine’s Direct Care Worker Shortage*, Maine Center for Economic Policy (February 2003), relying on the Occupational Employment Statistics Program, from the Maine Department of Labor.
Only the pay rate for consumer directed services is specified by the State (recently increased from $7.71 to $9.12/hour).

Based on the policy review to date, direct support professionals providing personal support are the only workers reported to receive benefits as part of their pay for services.

**Consumer Role in Hiring, Managing Workers**

Maine has several programs offering consumer direction, with others in the works. Table 2 lists existing consumer direction programs by age group.

**TABLE 2: Availability of Consumer-Directed PAS by Population Group**

<table>
<thead>
<tr>
<th>Population</th>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons with mental retardation or autism</td>
<td>NA</td>
<td>NA(^{13})</td>
</tr>
<tr>
<td>Persons with other disabilities</td>
<td>Medicaid State Plan Personal Care Services(^{14})</td>
<td>Consumer Directed Personal Care Services (MaineCare)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Consumer Directed Personal Assistance Services (MaineCare Waiver)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Consumer Directed Personal Assistance Services (State funded)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>State funded Home Based Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>State funded Homemaker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medicaid State Plan Personal Care Services(^{15})</td>
</tr>
</tbody>
</table>

*Eligibility Criteria.* The consumer directed programs currently in existence have two different approaches to eligibility for consumer direction.\(^{16}\)

**Consumer-Directed Personal Assistance.** The consumer-directed personal assistance programs are available to persons who can self-direct. Persons with a guardian or conservator are deemed ineligible. In addition, consumers must have the cognitive capacity to self-direct as measured during the MED assessment process. Consumers must agree to complete training and testing in order to verify they have the needed skills.

**Home Based Care and Homemaker and MaineCare State Plan Personal Care Services.** Under these programs, a consumer (or family member) can register as a personal care

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\(^{13}\) MR Services is currently developing an *Independence Plus* waiver that will introduce consumer direction for persons on that waiver.

\(^{14}\) A recent rule amendment allows both children and adults access to a family directed option.

\(^{15}\) A recent rule amendment allows both children and adults access to a family directed option.

\(^{16}\) It should be noted that persons with mental retardation have the option of hiring a worker through an agency or hiring a self-employed direct care worker. Although MR Services does not consider this working relationship to be “self-directed,” it does have some elements of a consumer or family-directed program.
agency solely for the purpose of directing his or her own care (or that of a family member). These recent amendments define a family member to include persons related by “blood, marriage, or adoption, or a significant other in a committed partnership.” The consumer or the family member serving as a Family Provider Agency must meet minimum standards for cognitive capacity. The home care coordinating agency (EIM) will conduct a criminal background check on the individual registering as a personal care agency.

Employer Support Services. The different consumer directed programs offer different levels of support and different levels of control to persons who hire their own workers.

MaineCare State Plan and MaineCare Waiver CD-PAS. For these two programs, the consumer has control over selecting and, managing workers and Alpha One takes responsibility for the fiscal activities (e.g., payroll, tax withholding, etc.). In addition, Alpha One provides training to the consumer on how to hire and manage the relationship with workers. Alpha One also provides a worker compensation option.

State funded CD-PAS. Under the state funded version of CD-PAS currently, the consumer is responsible for all aspects of the employer relationship including payroll, tax withholding, etc. The policy for this program has been revised to permit consumers to choose to continue with that responsibility or have Alpha One perform that task. Alpha One provides training on hiring and managing workers, as well as the fiscal and legal responsibilities of employment.

Home Based Care and Homemaker and Medicaid State Plan Personal Care Services. The home care coordinating agency (currently EIM) will conduct criminal background checks on the person registering as the personal care agency, but it is up to the consumer or family member to conduct a criminal background check on persons hired to provide services. The consumer or family member must use a fiscal intermediary approved by EIM.

At this time, no consumer directed programs offer emergency back up services or worker registries to support consumer direction.17

17 Through another Quality Choices project, which created the Maine Personal Assistance Services Association (PASA), a worker listing has been launched. This listing is to be managed by Maine PASA, not the State or its agent.
# Personal Assistance Services Policy Review

## Summary Matrix

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>NA</th>
<th>NA</th>
<th>NA</th>
<th>NA</th>
<th>NA</th>
<th>NA</th>
<th>NA</th>
<th>Mental retardation or autism</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional eligibility criteria</td>
<td>Needs physical assistance with ADLs &amp; IADLS</td>
<td>Needs physical assistance with ADLs &amp; IADLS (and nursing services)</td>
<td>Needs physical assistance with ADLs &amp; IADLS (and nursing services for some levels of service)</td>
<td>Needs cueing or physical assistance with ADLs &amp; IADLS (and nursing services for some levels of service)</td>
<td>Needs physical assistance with ADLs &amp; IADLS (and nursing services for some levels of service)</td>
<td>Needs cueing or physical assistance with ADLs &amp; IADLS</td>
<td>Needs physical assistance with ADLs or IADLS</td>
<td>Needs physical assistance, skills training, or supervision for ADLs, IADLS, community access, maintaining relationships, access to health and mental health services, communication</td>
<td>Needs cueing or physical assistance with ADLs (and nursing services)</td>
</tr>
<tr>
<td>Severity of disability</td>
<td>NA</td>
<td>Eligible for nursing facility level of care</td>
<td>Severity determines level of service</td>
<td>Eligible for nursing facility level of care</td>
<td>Severity determines level of service</td>
<td>Eligible for nursing facility level of care</td>
<td>Severity determines level of service</td>
<td>NA</td>
<td>Eligible for ICF-MR level of care</td>
</tr>
<tr>
<td>Other criteria</td>
<td>Ability to self-direct services, no guardian</td>
<td>Projected cost less than 100% of nursing facility services</td>
<td>Ability to self-direct services, no guardian</td>
<td>Projected cost less than 100% of nursing facility services</td>
<td>Not in hospital, nursing facility, residential care facility</td>
<td>Not in hospital, nursing facility, residential care facility</td>
<td>Not in hospital, nursing facility, intermediate care facility for persons with mental retardation</td>
<td>For “Katie Beckett eligibility category”</td>
<td>Projected cost less than 100% of nursing facility services</td>
</tr>
<tr>
<td>Serves children</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administering state agency</td>
</tr>
<tr>
<td>Governing regulation</td>
</tr>
<tr>
<td>Number served in program</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Eligibility Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
</tr>
<tr>
<td>Functional eligibility criteria</td>
</tr>
<tr>
<td>Severity of disability</td>
</tr>
<tr>
<td>Other criteria</td>
</tr>
<tr>
<td>Serves children</td>
</tr>
<tr>
<td>Services</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Monthly individual budget caps</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Access to Services</th>
<th>Standard tool for determining eligibility?</th>
<th>MED</th>
<th>MED</th>
<th>MED</th>
<th>MED</th>
<th>MED</th>
<th>MED</th>
<th>MED</th>
<th>No</th>
<th>MED*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Standard budgeting tool?</td>
<td>MED</td>
<td>MED</td>
<td>MED</td>
<td>MED</td>
<td>MED</td>
<td>MED</td>
<td>MED</td>
<td>No*</td>
<td>MED</td>
</tr>
<tr>
<td>Who conducts assessment?</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services or Authorized Homemaker Agency (Home Resources of Maine &amp; Aroostook Home Health Services)</td>
<td>Planning team</td>
<td>Goold Health Services</td>
</tr>
<tr>
<td>Who develops service plan?</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Goold Health Services</td>
<td>Home Resources of Maine &amp; Aroostook Home Health Services</td>
<td>Planning team</td>
<td>Provider agency</td>
</tr>
<tr>
<td>Who assists with implementing service plan?</td>
<td>Alpha One</td>
<td>Alpha One</td>
<td>Alpha One</td>
<td>EIM</td>
<td>EIM</td>
<td>Home Resources of Maine &amp; Aroostook Home Health Services</td>
<td>Individual service coordinator or private provider case manager</td>
<td>Provider agency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who monitors implementation of service plan?</td>
<td>Alpha One</td>
<td>Alpha One</td>
<td>Alpha One</td>
<td>EIM</td>
<td>EIM</td>
<td>Home Resources of Maine &amp; Aroostook Home Health Services</td>
<td>Individual service coordinator or private provider case manager</td>
<td>Provider agency</td>
<td></td>
<td></td>
</tr>
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</table>

**Worker Qualifications**

<table>
<thead>
<tr>
<th>Age</th>
<th>17+</th>
<th>17+</th>
<th>17+</th>
<th>16+</th>
<th>16+</th>
<th>16+</th>
<th>Not specified</th>
<th>Not specified</th>
<th>16+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legally responsible person? (e.g., spouse or parent of minor child)</td>
<td>Not permitted</td>
<td>Not permitted</td>
<td>Permitted</td>
<td>Not permitted</td>
<td>Not permitted</td>
<td>Permitted</td>
<td>Not permitted</td>
<td>Permitted</td>
<td></td>
</tr>
<tr>
<td>Type of worker</td>
<td>Personal attendant</td>
<td>Personal attendant</td>
<td>Personal attendant</td>
<td>Personal support specialist</td>
<td>Home health aide (HHA)</td>
<td>Certified nursing assistant (CNA)</td>
<td>Personal support specialist</td>
<td>Home health aide (HHA)</td>
<td>Certified nursing assistant (CNA)</td>
</tr>
<tr>
<td>Training</td>
<td>By consumer</td>
<td>By consumer</td>
<td>By consumer</td>
<td>PA: 40 hours training if not listed on CNA registry or completed CNA training in past 3 years. For new employees, 8 hour orientation and demonstrated competency if PA does not meet training and examination requirement</td>
<td>PA: 40 hours training program &amp; 8 hours of orientation, if not listed on CNA registry; or completed CNA training in past 3 years; HHA: 150 hour CNA training CNA: 150 hour CNA training</td>
<td>PA: 40 hours of training if not listed on CNA registry or completed CNA training within past 3 years HHA: 150 hour CNA training and agency orientation CNA: 150 hour CNA training</td>
<td>Determined by homemaker agency</td>
<td>Optional 45 hour training program</td>
<td>PA: 40 hours of training if not listed on CNA registry or completed CNA training within past 3 years HHA: 150 hour CNA training and agency orientation CNA: 150 hour CNA training</td>
</tr>
<tr>
<td>Other credentials</td>
<td>Competency certified by consumer</td>
<td>Competency certified by consumer</td>
<td>Competency certified by consumer</td>
<td>PA: Competency examination (required for PAs; offered to lapsed CNAs, trained in past 3 years).</td>
<td>PA: Competency examination (required for PAs; offered to lapsed CNAs, trained in past 3 years).</td>
<td>PA: Competency examination (required for PAs; offered to lapsed CNAs, trained in past 3 years).</td>
<td>PA: For consumer or surrogate directed</td>
<td>Demonstrated competency as alternative to training requirements</td>
<td>PA: Competency examination (required for PAs; offered to lapsed CNAs, trained in past 3 years).</td>
</tr>
<tr>
<td>CD-PAS MaineCare State Plan</td>
<td>CD-PAS MaineCare Waiver</td>
<td>CD-PAS General Fund</td>
<td>PCS MaineCare State Plan (Adults)</td>
<td>Elder and Adult MaineCare Waiver</td>
<td>HBC General Fund</td>
<td>Homemaker Services General Fund</td>
<td>Personal Support Services MR Waiver</td>
<td>PCS MaineCare State Plan (Children)</td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------</td>
<td>---------------------</td>
<td>----------------------------------</td>
<td>---------------------------------</td>
<td>-----------------</td>
<td>-------------------------------</td>
<td>----------------------------------</td>
<td>---------------------------------</td>
<td></td>
</tr>
<tr>
<td>Listed on CNA registry</td>
<td>Not required</td>
<td>Not required</td>
<td>Not required</td>
<td>PA: Not required</td>
<td>HHA: Required</td>
<td>CNA: Required</td>
<td>PA: Not required</td>
<td>HHA: Required</td>
<td>CNA: Required</td>
</tr>
<tr>
<td>Background check</td>
<td>Not required</td>
<td>Not required</td>
<td>Not required</td>
<td>Homecare or personal care agency must perform</td>
<td>Homecare or personal care agency must perform</td>
<td>Homecare or personal care agency must perform if agency based</td>
<td>Surrogate or consumer must perform if consumer directed</td>
<td>Homemaker agency must perform</td>
<td>Not required</td>
</tr>
</tbody>
</table>

**Reimbursement for Workers**

<table>
<thead>
<tr>
<th>Hourly pay</th>
<th>Consumer</th>
<th>Consumer</th>
<th>Consumer</th>
<th>Provider agency, consumer, surrogate</th>
<th>Provider agency</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, if agency based</th>
<th>Provider agency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal attendant/personal support specialist</strong></td>
<td>$9.12</td>
<td>$9.12</td>
<td>$9.12</td>
<td>$8.28&lt;sup&gt;a&lt;/sup&gt;</td>
<td>$8.28&lt;sup&gt;a&lt;/sup&gt;</td>
<td>$8.28&lt;sup&gt;a&lt;/sup&gt;</td>
<td>NA</td>
<td>NA</td>
<td>$8.28&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Home health aide</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>$8.43</td>
<td>$8.43</td>
<td>$8.43</td>
<td>NA</td>
<td>NA</td>
<td>$8.43</td>
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<tr>
<td><strong>Certified nurses aide</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>$9.35</td>
<td>$9.35</td>
<td>$9.35</td>
<td>NA</td>
<td>NA</td>
<td>$9.35</td>
</tr>
<tr>
<td><strong>Homemaker</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>$8.82&lt;sup&gt;b&lt;/sup&gt;</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td><strong>Direct support professional</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>$8.50 - $12.00&lt;sup&gt;c&lt;/sup&gt;</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Mental health rehabilitation technician</strong></td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
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</table>

**Benefits**

<table>
<thead>
<tr>
<th>Consumer</th>
<th>Consumer</th>
<th>Consumer</th>
<th>Provider agency, consumer, surrogate</th>
<th>Provider agency</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, if agency based</th>
<th>Provider agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Full package (if agency-based)</td>
</tr>
</tbody>
</table>

**Relationship to Worker**

<table>
<thead>
<tr>
<th>Managing employer of worker (hires, fires, trains, negotiates schedule)</th>
<th>Consumer</th>
<th>Consumer</th>
<th>Consumer</th>
<th>Provider agency, consumer, surrogate</th>
<th>Provider agency</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, consumer or surrogate</th>
<th>Provider agency, if agency based</th>
<th>Provider agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer agent (payroll, withholdings, etc.)</td>
<td>Alpha One</td>
<td>Alpha One</td>
<td>Choice: Consumer or Alpha One</td>
<td>Provider agency</td>
<td>Provider agency</td>
<td>Provider agency, consumer or surrogate</td>
<td>Provider agency, consumer or surrogate</td>
<td>Provider agency, if agency based</td>
<td>Provider agency</td>
</tr>
</tbody>
</table>

4
This policy review does not include services that are primarily instructional (e.g., habilitation or behavioral specialist services). Some analysis and recommendations in this report may apply to PAS tied to residential settings or to some instructional, skill development services. Another explanation for why PAS focus less on children’s needs: parents are assumed to have primary responsibility for assisting with certain activities, where a parent would have that responsibility for a child not having a disability.

The Department is currently testing a module of the MED designed specifically for children.

Recent rule change separated Assessing Service Agency and Home Care Coordinating Agency functions. Previously both performed by Alpha One.

All hourly pay rates for workers paid by home health or personal care agencies are estimated median wage, taken from *Without Care: Maine’s Direct Care Worker Shortage*, Lisa Pohlmann, Maine Center for Economic Policy (February 2003).

All hourly pay rates for workers paid by home health or personal care agencies are estimated median wage, taken from *Without Care: Maine’s Direct Care Worker Shortage*, Lisa Pohlmann, Maine Center for Economic Policy (February 2003).

All hourly pay rates for workers paid by home health or personal care agencies are estimated median wage, taken from *Without Care: Maine’s Direct Care Worker Shortage*, Lisa Pohlmann, Maine Center for Economic Policy (February 2003).

Average wages, according to February 2005 conversation with Susan Rovillard, Home Resources of Maine.

Based on department estimates, January 16, 2004.
Eliminating “Unnecessary” Inconsistency

One of the goals of this policy review is to eliminate “unnecessary” inconsistency across PAS program. For the purposes of this analysis, “unnecessary” inconsistencies are those differences in PAS programs which cannot be explained by differences in the needs of the people served. For example, differences in the level of service available across programs may or may not be related to differences in the level of need. These unnecessary inconsistencies might be attributable to differences in program history, or public or political support for a program, or different legal constraints on a program (e.g., a settlement agreement). Other “unnecessary” inconsistencies might be explained by differences in the way a program is funded or regulated (e.g., Medicaid restrictions on who can serve as a direct support worker do not apply to state funded programs). Some perceived differences may be outside the scope of this analysis, resulting from variations in the way providers interpret or apply state policy.

As a policy review, it is difficult to determine which differences are or are not explained by differences in the population served. No attempt was made to measure and compare level of need and level of service across PAS programs. Instead, where a difference is found to be “unnecessary,” the conclusion is based on an analysis of policies and a deduction about the impact of those policies. In addition, other parts of this report implicitly address differences across programs in the course of identifying opportunities for increasing consumer choice and control across programs. This section will not repeat that analysis. Instead, this section focuses on inconsistent, or inequitable, access to PAS – whether access to personal assistance is equitably distributed to those who need it.

Inconsistent Access and Eligibility for Services
The State uses eligibility criteria to allocate personal assistance services across Maine citizens. In some cases, the eligibility criteria controlling access to personal assistance will create very different outcomes, depending on the type of impairment and access to resources. Eligibility criteria for PAS may produce an inequitable result in at least two different ways.

Eligible versus Ineligible. Defining an equitable allocation of resources will depend on one’s policy goal. If the State’s policy goal is to assure health and well-being in a community-based setting, the State will determine who it can safely serve in a community setting and the level of service needed to safely support living in a community setting. If the goal is to support comparable levels of independence across all persons with disabilities, the State might focus less on the severity of a disability and more on the nature of a disability and the barriers it creates to community access. The distinction is illustrated by applying existing eligibility criteria to the following hypothetical individuals:

- Person A cannot safely live in the community without personal assistance. She requires assistance getting out of bed in the morning, showering and getting dressed. Once out of bed and dressed, she is able to drive to work, pick up groceries on the way home, and make dinner. Person A is eligible for PAS available for elders and
adults. These services not only assure a level of health and well-being, they support Person A’s independence in her community.

- Person B can safely live in the community without PAS. He has both a visual and hearing impairment, but does not need help with self-care. Once out of bed and dressed, however, Person B is limited in what he can do independently. For example, he is not able to drive to work or find groceries on a shelf without assistance. Because Person B does not require assistance with self-care, he is probably not eligible for personal assistance services (with the possible exception of state funded, in-home homemaker services, capped at 10 hours per month). While Person B’s physical health and well-being are not at issue, Person B has less ability to engage in the everyday activities of life.

- Person C has a brain injury. Person C does not require physical assistance to get out of bed and get dressed, but he needs someone to remind him to mail the rent check or the phone bill. Person C cannot drive because he is forgetful and easily distracted. He needs assistance managing his behavior. This person is not eligible for any PAS program. Like Person B, his physical health and well-being are not immediately at issue, but his ability to maintain his independence is severely limited by his disability.

If the State’s goal is to assure a certain level of health and well-being, the distribution of resources across Persons A, B and C, in the short term at least, supports that goal. On the other hand, if the State’s goal is to assure a certain level of independence, the allocation of PAS results in a very uneven distribution of access to everyday life activities. The PAS allocated to Person A “level the playing field” with persons having no disability; Person A can attain a comparable status of well-being and independence in a community setting. For Persons B and C, a lack of access to PAS means they face barriers to community participation, and a limited ability to sustain their independence.

Program A versus Program B. In addition to screening people in and out of PAS programs, eligibility criteria sort people across PAS programs. Ideally, the eligibility criteria would equitably distribute access to the appropriate level of services. However, diagnosis driven eligibility criteria can create inconsistent access to services relative to the level of need. For example, a person with mental retardation can access individualized personal supports, 24 hours a day, through Program A, the MR waiver. A person with a comparable level of need, but having a brain injury instead of mental retardation, does not have access to individualized personal assistance, 24 hours a day. Instead, this person accesses services through Program B, for elders and adults. These services are capped well below the level available under the MR waiver.

Inconsistent Access and the Budget Determination Process

Provider Involvement in Creating Individual Budgets. There are a variety of ways that PAS programs determine an individual’s budget for PAS. One of the key differences between these programs is the role they give the provider of services in evaluating an individual’s need for services. For agency-based PAS programs administered by BEAS, an independent agency administrator a standardized assessment tool which is used to determine the individual budget.
The budget is then handed over to another provider for implementation. In contrast, for MR waiver services, providers participate in the Person Centered Planning process, helping to identify services to be included in the service plan before a budget is determined. Once the plan is developed, the provider negotiates with DHHS for the cost of providing the services it helped to identify as needed. There is no standard rate for determining the budget for providing services. For the consumer-directed PAS administered through Alpha One, Alpha One administers a standardized assessment tool to determine the level of need. Alpha One then assists the individual in implementing a plan, providing payroll and other services. In return, for Medicaid-reimbursed services, Alpha One receives a percentage for every hour of personal assistance service provided.

There is no systematic analysis demonstrating that Maine’s PAS providers inflate the service needs of those they serve. At the same time, in other fields, a growing body of research demonstrates wide variation in clinical decision making, unrelated to differences among the individuals being served. Studies also suggest that, within this range of discretion, providers are prone to assess a higher level of need for their services. Some attribute this tendency to financial incentives, others to philosophical reasons. In either case, more likely than not, where one program has an independent assessor determining the level of need and another includes the provider in that process, a systematic bias is created across programs, resulting in a less than equitable distribution of resources.

*No Standard Process for Determining Level of Need and Budgets.* For MR waiver services, there is no standardized assessment tool for determining whether a person is eligible for MR waiver services; there is no standardized assessment process for determining what services a person needs. As a result, individual budgets can be influenced by a number of variables that are not related to the individual’s need for services. These factors might include the individual’s ability to advocate for him or herself, the assertiveness (or existence) of a support network to advocate on the consumer’s behalf, the provider’s skill at advocating for services, etc. Through its *Money Follows the Person* grant, MR Services is developing a standardized assessment tool. Implementation of this tool will reduce the unnecessary inconsistency in allocation of PAS.

**Inconsistent Access and Worker Pay**

It is difficult to compare worker pay across programs. It is also difficult to determine whether differences in pay might be related to differences in qualifications and differences in the kind of work performed. At a minimum however, it seems safe to say that where one program pays benefits and the other does not, for similar lines of work, there is an inequitable allocation of resources. All else equal, MR Services is probably better able to attract and retain a better quality workforce than those programs that do not reimburse for benefits.

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18 Under DHHS’ *Money Follows the Person* grant, standardized rates and a standardized individual budgeting tool will be developed and implemented.
19 Pursuant to legislation transferring consumer directed programs back to BEAS, an independent assessment will be used to conduct the assessment and develop the individual budget.
Inconsistent Access and Waiting Lists

For some programs, getting past the eligibility threshold for a program does not mean entry into a program. Entry into state funded PAS programs or onto a Medicaid waiver may be limited by available funds. (Persons eligible for Medicaid state plan services are entitled to those services and cannot be waitlisted based on funding availability.) A waiting list is itself evidence of inequitable access: persons with comparable levels of need are receiving different levels of service. Does the waiting list result because, with the limited resources available, the State can only adequately support a limited number of people? Or does the waiting list result because the State has provided a generous level of support to those first in line and run out of resources for those coming late? Does the State have a measure for deciding what an individual “needs” in order to live in the community, what an individual “wants” in order to enhance his or her life, and where the State’s threshold is in meeting these “needs” and “wants?”

Recommendations for Eliminating Unnecessary Inconsistency

To see how these recommendations apply across PAS programs, see the summary matrix, RECOMMENDATIONS FOR ELIMINATING UNNECESSARY INCONSISTENT ACCESS TO PAS, at the end of this section.

1. **Develop common goal for allocating PAS.** To promote equity across programs, the State should define a shared goal for its PAS programs. It would be no small challenge to develop consensus on a goal. (Is the State trying to support a minimum level of health and well-being in a community-based setting? Or is it supporting a certain level of engagement in community life? Does the State’s goal vary with available resources?) Developing consensus on how to apply that goal across population and age groups would also be challenging. (Is the State supporting independence, inclusion or recovery? What is the prevailing norm of independence or community inclusion for a young adult? An elder? How do we measure our success at achieving our goal?) At the same time, the State faces an ongoing struggle, internally and externally, to justify or challenge the existing allocation of resources. Without a standard for evaluating program goals and the allocation of resources, these battles are often won based on political might rather than rational decision making. Without a commonly shared threshold for distinguishing between “needs,” “wants,” and which of either the State will pay for, the State is unable to address perceived inequities across programs and within programs, and between those receiving services and those waiting to receive services. This deficiency is all the starker in the context of the current budget crisis, where current funding cannot be sustained.

2. **Develop comparable measures of need across PAS programs.** While a clinical diagnosis may be important to determining how to meet a need, diagnosis should not determine how resources are allocated. Within programs, different levels of personal assistance are made available based on an individual’s need for assistance with ADLs and IADLs, and the degree of cognitive impairment. Defining a comparable measure of these needs across population groups would enable the State to work toward equitably distributing resources across these groups, consistent with its common goal.
3. **Develop budgets with an independent assessor using a standardized tool and process for determining level of need.** Some object to the independent assessor as a “gatekeeper,” limiting access to services. Yet gatekeeping – the allocation of resources across competing needs – is a core government function. The independent assessor is a tool for ensuring that the gatekeeping function is done rationally and equitably. Attacks on the gatekeeping function are better directed at the criteria for allocating resources, the level of resources available to be allocated, and the training and consistency of those doing the allocation.

4. **Develop consistent worker credentials and pay scales across programs.** An analysis of the core competencies required of direct care workers, across PAS programs, could be used to develop a modularized training and credentialing requirement. In addition to providing a rational basis for differential pay, it could provide an integrated career lattice for workers permitting lateral movement and across programs.
## Personal Assistance Services (PAS) Policy Review

### Recommendations for Eliminating Unnecessarily Inconsistent Access to PAS

#### Summary Matrix

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>CD-PAS MaineCare State Plan</th>
<th>CD-PAS MaineCare Waiver</th>
<th>CD-PAS General Fund</th>
<th>PCS MaineCare State Plan (Adults)</th>
<th>Elder and Adult MaineCare Waiver</th>
<th>HBC General Fund</th>
<th>Homemaker Services General Fund</th>
<th>Personal Support Services MR Waiver</th>
<th>PCS MaineCare State Plan (Children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop common goal across programs for supporting independence, inclusion and recovery</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Develop comparable measure of need for allocating resources across persons needing personal assistance</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Use independent assessor (other than provider of services) to determine eligibility, assess level of need</td>
<td>✓(^a)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Use standardized assessment tool and process for determining eligibility, level of need &amp; budget</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓(^b)</td>
</tr>
<tr>
<td>Identify core competencies and program specific competencies across programs</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rationalize pay and benefits consistent with required competencies, across programs</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

\(\sqrt{}\) = Recommendation applies to program

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\(^a\) The Legislature has required an independent assessor for the three CD-PAS programs.

\(^b\) MR Services is planning to develop a standardized budgeting tool under its *Money Follows the Person* grant.
Increasing Consumer Control

Another goal of this policy review is to identify opportunities for increasing consumer control over PAS. “Consumer control” is defined as the consumer’s right to make decisions or choices:

This right to make decisions is built upon the fundamental premise that the consumer is the expert on his or her service needs. For some more complex services, a consumer may need to consult with professional or clinical expertise to make better informed decisions about how to meet service needs; still, even with professional expertise involved, the consumer retains the right to participate in assessing need, evaluating options and deciding on a course of action. Because the consumer is the expert on how to meet his or her needs, consumer control is also expressed when that expertise is applied to the design, development, operation and evaluation of home and community-based services.20

Consumer control, or consumer direction, exists on a continuum, with a consumer having an opportunity to control services to varying degrees, depending on program design and other factors.21 In an agency-based program, a consumer might direct his or her services by expressing a preference for a particular worker or a particular time of day for receiving a service. On the other end of the spectrum, a consumer might have control over how to spend a cash budget.

The Potential Reach of Consumer Control

In our society, we value individual “autonomy” or the right of individuals to make decisions for themselves. The right to make decisions is always limited by other considerations, including the impact a decision has on others, the range of choices, and available resources.

<table>
<thead>
<tr>
<th>Key Definitions</th>
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<tbody>
<tr>
<td><strong>Accountability.</strong> The obligation to report, explain or justify something.</td>
</tr>
<tr>
<td><strong>Authority.</strong> The power to judge, act or command.</td>
</tr>
<tr>
<td><strong>Autonomy.</strong> The right of an individual to make decisions. In the context of health care or long term care, a health care provider can educate an individual about his or her options but the individual makes the decision.</td>
</tr>
<tr>
<td><strong>Responsibility.</strong> The obligation to answer or be accountable for something within one’s power or control.</td>
</tr>
<tr>
<td><strong>Right.</strong> That which is due to an individual legally or by moral principle.</td>
</tr>
</tbody>
</table>

20 Definition of “Consumer Control” adopted by Person Centered Services Technical Advisory Group, as derived from Consumer Direction in Home and Community Based Services: An Assessment Guide for States, National Association of State Units on Aging.

In general, we link control over a decision with responsibility for the decision. The person making a decision is usually responsible for its outcome. Correspondingly, the person having responsibility for a decision should have a right to make it.

For privately funded services, an individual might have to share control over services with an insurer or a provider. For publicly funded services, where the State is held accountable for the expenditure of public funds, a consumer will have to share control with the State and providers. Consumer control will be circumscribed by the amount of control that the State and providers retain in order to satisfy their responsibilities.

The State’s Responsibilities. The State has a number of responsibilities, some defined by the federal government, some defined by the legislature, and some defined by public expectations. Some of these responsibilities include:

Assuring quality and protecting health and welfare. The federal government requires states administering Medicaid programs to have methods and standards for assuring that services are of high quality. For persons served under waivers, the State must have safeguards in place to protect their health and welfare. These safeguards must include standards for providers of waiver services, and assurance that state licensure and certification requirements are met. In addition to its legal obligations, the State may be held accountable politically for a bad outcome that draws public attention, whether or not the State complied with legal requirements.

Accounting for the appropriate use of public funds. The legislature, the federal government, and the public all have an interest in how public dollars are spent. The State is responsible for demonstrating that public money is spent as intended and legally permitted, and not wastefully. The State must ensure that the services it pays for were actually received and that the types of services paid for are permitted under law. The State may also be challenged by the public’s expectation that its money be distributed fairly, however that might be defined.

Otherwise assuring compliance with the law. In addition to the responsibilities above, the State is responsible for making sure that administration of PAS complies with the other laws. For example, for Medicaid funded services, the federal government limits eligible providers to those “not legally responsible” (i.e., spouses of recipients or parents of minor recipients). The State also has to comply with state licensing law, including licensing requirements for certified nursing assistants governed by the State Board of Nursing and the licensing requirements for home health aides governed by the Bureau of Medical Services.

The Provider’s Responsibilities. Provider agencies that hire personal assistants, and personal assistants working independently or for an agency have their own points of accountability. Some of these responsibilities include:

Complying with program requirements. Providers and workers are responsible for making sure that they only seek reimbursement for services within the scope of permitted
services; that services are delivered by qualified personnel, in compliance with program requirements; and that they can document that services were delivered in compliance with program requirements.

Complying with licensing and certification laws. A licensed provider or worker must comply with the laws governing the scope of activities the provider is licensed or certified to perform.

Not causing harm or protecting against harm. Under tort law, a provider agency or a personal assistant can be held accountable if their conduct caused harm to an individual, or if it failed to protect a person from harm when it had a duty to do so.

Complying with insurance requirements. Providers are also responsible to their insurers for complying with restrictions imposed by insurers. Workers’ compensation insurance, for example, may limit the scope of activities that a provider can perform, if the activity poses a risk to workers. For example, to prevent injury to a worker, an agency may require the use of a Hoyer lift for lifting a consumer, whether the consumer wants to use a Hoyer lift or not.

Operating a financially viable business using sound business practice. Whether operating for profit or not for profit, a provider agency must operate its business to be sustainable. A provider agency must respond to budget constraints that limit its capacity to provide services.

The Consumer’s Responsibilities. The consumer’s responsibility will largely be a function of the level of control he or she is permitted by the State or providers. At a minimum, where a consumer has control over choices about self-care, a consumer is responsible for those choices. Where a consumer has control over selecting and managing workers or how to allocate resources, the consumer has responsibility for making choices that best meet his or her needs and complying with program requirements.

Consumer Control and the Design of Services

Because the State is responsible for ensuring that services comply with governing law, that resources are distributed equitably and appropriately, that providers have the capacity to support service design, and that the well-being of vulnerable populations is protected, the State is responsible for designing services. While consumers do not control these decisions, to make sure that services are designed to meet consumer needs, the State should include consumer input in service design and improvement. The State will have a similar interest in provider input.

TABLE 3 describes a possible distribution of decision making roles for the State, providers and consumers with respect to service design and improvement.
TABLE 3. Possible Distribution of Decision Making Roles for Service Design

<table>
<thead>
<tr>
<th>STATE</th>
<th>PROVIDER</th>
<th>CONSUMER</th>
</tr>
</thead>
</table>
| The State decides how to design service, within federal and state program constraints:  
- Who is eligible  
- How eligibility is determined  
- How an individual budget is determined  
- Program budget for PAS  
- Minimum provider and worker qualifications for reimbursement by the State  
- Scope of PAS (within boundaries of program purpose and budget limits)  
- The range of permitted uses for public funds (e.g., assistive technology) and the systems for tracking  
- How to respond to stakeholder input on ways to modify services | Provider/Worker offers expertise on how best to design services within existing constraints and capacity, good professional and business practice. E.g., Provider/Worker helps to define:  
- Available range of services and supports  
- Available scope of services for PAS  
- Minimum qualifications for PAS workers  
- How to respond to consumer input on ways to modify services to better meet consumer preferences | Consumers offer expertise on how best to meet their needs in the design of services and programs. E.g., Consumer helps to define:  
- Needed and preferred range of services and supports  
- Needed and preferred scope of services for PAS  
- Needed and preferred qualifications and characteristics for PAS workers |

Consumer Control and the Delivery of Services

The opportunity for sharing control is greatest in the delivery of services. Potential areas for consumer control include:

*Allocating the budget.* The State can set standards and monitor how funds are spent. Within these constraints, depending on program design, the consumer could exercise control over how the budget is spent across services and other options, and across providers. Consumers may find that a purchase of certain alternative goods, services or equipment can serve as a substitute for PAS or enhance the efficiency or effectiveness of PAS.22 The range of permitted uses might include alternative services (e.g., a laundry service, grocery service, etc.) or assistive devices or other hard goods that could substitute for or reduce dependency on a direct support worker (e.g., a microwave or washer and dryer).

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22 See Mark R. Meiners, Dawn M. Loughlin, Michele D. Sadler & Kevin Mahoney, “Clarifying the Definition of Personal Care: Findings on the Purchases of Goods and Services under the Cash and Counseling Demonstration and Evaluation Cash Options in Arkansas and New Jersey,” University of Maryland Center on Aging (Draft, March 2, 2004), reporting findings that permitting the purchase of personal care related services, equipment, and goods, can enhance comfort, safety, mobility and independence.
Scope of services. The State defines the scope of PAS to be consistent with the program purpose and governing federal and state law. However, within those constraints, the consumer can exercise flexibility in defining the range of tasks desired of a personal assistant.

The selection and management of workers. The State has an interest in setting parameters around who can provide PAS to assure workers meet minimum standards for quality, but still allow consumers to recruit, select and manage their own workers within the State’s parameters.

Determining where, when & how PAS are provided. The State or the provider might impose some restrictions on where, when and how PAS are provided, depending on budget, liability and other constraints. However, within those constraints, the consumer could make decisions about where, when and how services are delivered.

Table 4 describes a potential distribution of decision making authority for the delivery of services.

**Table 4. Possible Distribution of Decision Making Roles for Service Delivery**

<table>
<thead>
<tr>
<th>STATE</th>
<th>PROVIDER</th>
<th>CONSUMER</th>
</tr>
</thead>
<tbody>
<tr>
<td>State (or State’s agent) decides:</td>
<td>Provider/Worker decides:</td>
<td>Consumer decides, within constraints imposed by State and provider responsibilities:</td>
</tr>
<tr>
<td>• If an individual is eligible for a program</td>
<td>• The scope of PAS they are willing to provide, within constraints imposed by program requirements, licensing regulations, insurance policies, liability concerns</td>
<td>• How to distribute the individual PAS budget to best meet needs, as permitted by the program</td>
</tr>
<tr>
<td>• The budget for services available to an individual</td>
<td>• How/whether to satisfy consumer’s preferences for how, where &amp; when PAS is delivered, within limitations imposed by the program, reimbursement, etc.</td>
<td>• Scope of PAS tasks provided</td>
</tr>
<tr>
<td>• The services an individual is eligible to receive</td>
<td>• Whether to provide PAS services at the rate of reimbursement, under consumer’s or State’s terms</td>
<td>• How much control to exercise over selection and management of providers, as constrained by available supports</td>
</tr>
<tr>
<td>• Whether a provider or worker meets minimum requirements for reimbursement</td>
<td>• Whether other quality assurance requirements are met</td>
<td>• How services are provided (e.g., whether or not to use Hoyer lift)</td>
</tr>
<tr>
<td>• Whether the individual is using services as permitted and defined under the service plan</td>
<td></td>
<td>• Where and when services are provided (e.g., on the job, at home, in time for work)</td>
</tr>
</tbody>
</table>

**Consumer Control and the Quality of Services**

The State has responsibility for complying with federal and state quality assurance and improvement requirements. As a result, the State retains ultimate control over the design of its
quality assurance and quality improvement program. However, the State’s assessment of quality will depend to some degree on the consumer’s assessment of quality. TABLE 5 describes a potential distribution of decision making authority for evaluating the quality of services.

TABLE 5. Possible Distribution of Decision Making Roles for Quality

<table>
<thead>
<tr>
<th>STATE</th>
<th>PROVIDER</th>
<th>CONSUMER</th>
</tr>
</thead>
<tbody>
<tr>
<td>The State decides how to design the QA function to comply with law, to satisfy its responsibility for protecting the health and welfare (and other goals) of persons receiving PAS; State decides how to incorporate assessment data into program operations</td>
<td>Providers/Workers offer expertise on how to design QA function consistent with provider capacity to satisfy requirements and measure performance</td>
<td>Consumers offer expertise on how best to design QA functions to measure a consumer’s assessment of quality, to monitor and assure quality while minimizing intrusion on consumer control</td>
</tr>
<tr>
<td>Consumers report opportunities for improving services</td>
<td>Consumers respond to surveys measuring consumer experience</td>
<td>In some cases, consumer takes corrective action (e.g., fires worker)</td>
</tr>
</tbody>
</table>

Factors that Limit Consumer Control

The previous section identified potential decision making roles for the consumer. This section identifies a number of factors that limit the consumer’s ability to exercise control. Among these factors are:

- Consumer decision making capacity;
- Risk and the State’s or providers’ incentive to avoid risk;
- Availability of choice;
- Attitudes, training and role definition for the state workers and providers.

The degree to which these factors limit consumer control can be influenced by state policy and culture. Each factor is discussed at greater length below.

*Decision Making Experience and Capacity.* Consumer direction is “premised on the existence of an autonomous consumer who is cognitively, emotionally, and physically able to act as an informed and voluntary decision maker.”23 In some cases, a person’s disability might impair his or her ability to make decisions. Alzheimer’s, a brain injury, mental retardation and other types of disabilities can impair a person’s ability to understand and evaluate potential consequences. The capacity to make decisions can vary depending on the type of decision. For example, a person might not be able to understand the consequences of certain financial decisions but might be capable of making decisions about the kind of personal assistance he or she might need. The

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capacity to make decisions might also vary over time, with decision making capacity progressively worsening or periodically fluctuating, depending on the underlying condition causing the impairment.

If the goal is to maximize consumer control, ideally, the fact that a person is unable to make some decisions would not disqualify that person from making any decisions. Ideally, a consumer’s control over decisions would be modified to match the consumer’s ability to make decisions. A person with the capacity to make most decisions would have the right to make those decisions but not others. If a person’s ability to make decisions changes, the person’s authority to make decisions would also change.

In the real world, there are a number of challenges to having such a fluid approach to decision making capacity. It is very difficult to define and measure decision making capacity, particularly when capacity is fluctuating. In addition, where a court finds decision making capacity is impaired, it identifies a guardian to make decisions on behalf of the individual. Once legal authority has transferred from the individual to a guardian, the individual does not have a legally recognized right to make decisions for him or herself; the State or provider cannot recognize the decisions of an individual under guardianship. Guardianship does not recognize shared or flexible decision making roles.24

“Assisted competence,” or supported decision making, offers a less formal, more flexible way to address impaired decision making capacity. Assisted competence parallels the concept of PAS as a service compensating for an individual’s disability. Under an assisted competence approach, an individual might receive a range of supports that assist the individual in decision making while preserving his or her legal rights.25 A support network comprising family members or friends provide advice or assistance, helping the individual understand their choices. The individual, not a guardian, is the person with legal authority to make the decisions. Like PAS, the level and kind of support can vary with the level and kind of impairment.

For persons with very impaired decision making capacity, supported decision making might not be an option. As an alternative to the legal transfer of decision making authority, another model is an informal designation of a substitute decision maker. For example, until a recent amendment, under BEAS state funded home based care program, a surrogate was chosen based on the surrogate’s ability and willingness to act on behalf of the individual. Criteria included a person’s:

- strong personal commitment to the consumer,
- knowledge about the consumer’s preferences; and
- an agreement to visit the consumer at least every two weeks.

24 In some cases, courts limit the scope of the guardianship and preserve some decision making authority for the individual. In reality, these distinctions are not always recognized, as demonstrated by the eligibility criteria for Maine’s consumer directed programs: the fact of guardianship excludes a person from eligibility, without reference to whether or not the guardianship is limited.
Both of these informal approaches assume that an individual has a natural support system of friends and families who can and are willing to provide assistance with decision making, or serve as surrogate. For persons without family or friends to serve in these roles, access to supported or surrogate decision making will be limited. For persons with natural supports assisting with decision making or making decisions, the State and providers have responsibility for monitoring the quality of substitute decision making, to ensure that the individual’s health and well being is protected. In addition, the State will have to set standards for the roles friends and families can play. These standards will have to address the potential conflict of interest created when a family member serving as a substitute decision maker then decides to hire him or herself as an individual’s personal attendant.

Whether or not it is anticipated that an individual’s decision making capacity will fluctuate or decline, advance planning (including crisis planning for those with psychiatric disorders), will greatly enhance individual control and minimize provider or state risk.  

### Alternative Decision Making Models

**Independent Decision Making.** The consumer can make independent decisions. The consumer can choose to delegate some or all aspects of decision making to a surrogate.

**Supported Decision Making.** The consumer can make some independent decisions, but requires assistance for others. The consumer directs care, with support from family members or friends. The consumer can choose to delegate some or all aspects of decision making to a surrogate.

**Substitute Decision Making.** The consumer cannot make independent decisions. A surrogate directs care on behalf of the consumer. The surrogate is identified from among the consumer’s natural supports. Consumer preference is factored into decision making, where preference is expressed.

### Consumer Control and Risk for Providers and the State

In some cases the distribution of responsibility, or accountability, among consumers, the State, and providers, will be clearly defined and consistent. In many others, however, accountability will be unclear or unpredictable. As a result, it is not always possible to directly link responsibility for an outcome of a decision with control over the decision.

Sorting out responsibility for a bad choice can be complicated, depending on a retrospective interpretation of what happened. For example, a provider might appropriately be responsible for a person’s bad choice if the person was incompetent to make decisions and the provider should have known the individual was incompetent. Or maybe the provider failed to appropriately monitor the person’s safety, and a surrogate decision maker was able to neglect or abuse the person. But with a different set of facts, a provider might not have been able to prevent the harm. Maybe the individual was competent but knowingly made a bad choice. Or perhaps the

provider appropriately monitored the individual’s health and well being but was unable to detect signs of abuse or neglect.

Unfortunately, in these circumstances and in many others, the standard for determining accountability, *e.g.*, when a person is “competent” or when someone acted “appropriately,” are open to interpretation. Sometimes the standard applied retrospectively after a bad outcome is different from the standard advocated prospectively when individual autonomy is at issue. In reality, especially for persons perceived to be vulnerable, it is possible a state agency or provider, legally or politically, will be held responsible simultaneously for both protecting the people it serves while also giving them a greater share of control over decisions.

To minimize the risk of being held accountable for someone else’s decisions, the State and providers have an incentive to maximize their own control, necessarily reducing the consumer’s control. In reality, however, risk can only be managed, not avoided entirely. In fact, according to some, over-regulating a risk by imposing constraints and restrictions can actually increase risk. In this view, overly restrictive “protections” undermine the community relationships essential to better lives for all people: “the qualities that offer people with disability security are the same qualities that define a good life: caring relationships, opportunities for participation and association, and power over the conditions of everyday life.”

Thus, in the context of consumer direction, risk management means developing quality management tools and functions that support a state’s need to monitor and manage quality, while imposing minimal intrusion on consumer decision making. Some of these functions might include:

- Setting standards for worker qualifications, seeking consumer expertise to shape standards.

- Using a provider agency, fiscal/employer agent, or service coordinator to monitor progress toward goals under the service plan. The monitoring function can also trigger a predetermined response when implementation of a service plan looks very different from what was expected.

- Developing a complaint and grievance hotline for immediate response when a problem arises; the hotline needs to be tied into the quality assurance and quality improvement infrastructure to ensure that systemic problems are addressed.

In addition, a shift in responsibility might mean that the State limits how much risk it, or a provider agency, takes on by entering into a negotiated risk contract, in which the consumer documents his or her understanding of the potential consequences connected to a particular choice and accepts responsibility for that choice. As discussed previously, providers can

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As the ultimate fail-safe, a consumer that cannot make decisions without creating unacceptable risk for him or herself, the State, or others may lose the right to direct his or her own services.

**Availability of Choice.** Consumer control is premised on the availability of choice. If there are no options to choose among, a consumer’s right to make decisions is not meaningful. The availability of choice is discussed further in the next section.

**Attitudes, Training and Role Definition.** In traditional provider/consumer relationships, the consumer defers to a provider as an “expert.” While a provider or a direct support worker does have expertise, a consumer also has expertise about personal needs and preferences. Training curricula for direct support workers, service coordinators, and other providers need to emphasize the role of consumer decision making.

Consumer control can also be undermined when a provider has a conflict of interest. For example, some case managers have responsibility for being both the “gatekeeper” (determining eligibility and the level of service) and advocating for an individual. Some case managers are
responsible for helping an individual find services but have an incentive to steer a consumer to their own provider agency.

Administrative Appeals and Litigation. Like the liability system, the administrative appeal process is put in place to protect the individual. Individuals have a right to appeal certain decisions made by a state agency (or its delegate) to make sure that decisions are fair and legal. For example, an individual might argue that the state unfairly reduced or denied services. The individual can challenge these decisions through a formal process in which the state agency is required to review its decision to ensure compliance with its own rules and other law governing the program.

According to some observations, for some PAS programs, the State will revise rules in response to a successful administrative appeal to more specifically describe its policy. According to these observations, increased specificity means increased rigidity, and less room for consumer control. The question of whether this increased rigidity is an inevitable outcome of the dispute resolution process bears further exploration.

Recommendations for Expanding Consumer Control
To see how these recommendations apply across PAS programs, see the summary matrix, RECOMMENDATIONS FOR INCREASING CONSUMER CONTROL OVER PAS, at the end of this section.

1. **Expand supportive and substitute decision making options.** A critical component of supportive or substitute decision making models will be standards for selecting and training supportive and substitute decision makers, and mechanisms for monitoring quality. Ideally, there would be alternative strategies for those who do not have a natural support system.

2. **Give consumers the right to choose among a range of permitted uses for PAS budgets.** Through the budgeting process, the State allocates a certain level of resources to each individual. Instead of automatically converting that budget into a service plan, the consumer should have an opportunity to allocate those resources across a range of permitted uses that potentially enhance the efficiency or effectiveness of traditional PAS.

3. **Expand to all population groups the option to select and manage direct support workers.** With supported or substitute decision making options available, consumer direction of workers should be available across programs. Standards for worker qualifications have to satisfy the State’s interest in quality assurance and the consumer’s interest in finding the right worker. The State should explore the trade-offs of allowing the consumer to negotiate a higher pay rate to retain workers that are more efficient and provide better service.

4. **Maximize flexibility in the service plan.** In developing the service plan, the consumer should be able to decide whether or not to use personal assistance on the jobsite or another setting and whether to pay a job coach, a co-worker, or a friend to provide personal assistance in these different settings. In implementing the service plan, the state should reorient provider accountability to the consumer rather than the State, holding provider agencies responsible for responding to consumer preference on when, where and how services are provided.
5. **Develop a conflict-free service broker option to support consumer control over service planning and evaluation.** The service broker would provide a service coordination function, assisting an individual with developing a service plan and periodically monitoring and evaluating the effectiveness of the service plan. However, the service broker would have no role as a “gatekeeper” to services and would not have an incentive to steer the individual to particular services or service providers.

6. **Expand consumer role in the design of services and the evaluation of service quality.** Implicitly, quality improvement mechanisms provide a vehicle for soliciting consumer input; satisfaction surveys, focus groups, and other tools can be used to identify opportunities for improving services. An *ad hoc* consumer advisory body can be formed in the design or redesign phase for a service. A hotline to capture consumer complaints and opportunities for improvement should be linked into the quality assurance and improvement process across programs. As demonstrated under the Maine’s *Quality Choices* grants, consumers also play a valuable role in defining measures of quality and participating in the measurement of quality.
## Recommendations for Increasing Consumer Control over Personal Assistance Services

### Summary Matrix

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>CD-PAS MaineCare State Plan</th>
<th>CD-PAS MaineCare Waiver</th>
<th>CD-PAS General Fund</th>
<th>PCS MaineCare State Plan (Adults)</th>
<th>Elder and Adult MaineCare Waiver</th>
<th>HBC General Fund</th>
<th>Homemaker Services General Fund</th>
<th>Personal Support Services MR Waiver</th>
<th>PCS MaineCare State Plan (Children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offer supportive decision making option:</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
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</tr>
<tr>
<td>• Define standards for selecting supportive decision makers, training, monitoring performance</td>
<td>√</td>
<td>√</td>
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<td>√</td>
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<tr>
<td>Offer substitute decision making option</td>
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<tr>
<td>• Define standards for selecting substitute decision makers, training, monitoring performance</td>
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<tr>
<td>Give consumers the right to choose among a range of permitted uses for PAS, including assistive devices and alternative service options.</td>
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<tr>
<td>Maximize flexibility in service planning</td>
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<td>√</td>
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<tr>
<td>• Eliminate limitations on where PAS can be provided (including on job site)</td>
<td>√</td>
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<tr>
<td>• Hold providers accountable for responding to consumer preference on when, where, and how services are provided (Explore whether service authorizations are unnecessarily restrictive)</td>
<td>√</td>
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<tr>
<td>Develop option for consumers to select and manage workers</td>
<td>√</td>
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<td>√</td>
<td>√</td>
<td>√</td>
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</tr>
<tr>
<td>• Provide consumer training to recruit, select and manage workers</td>
<td>√</td>
<td>√</td>
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<td>√</td>
<td>√</td>
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</tr>
<tr>
<td>• Work with consumers to make sure provider qualifications meet State’s quality assurance needs while minimizing limits on consumer control</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
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</tr>
<tr>
<td>• Examine trade-offs of permitting consumers to set the reimbursement rate for workers that they hire, within a range</td>
<td>√</td>
<td>√</td>
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<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
</tbody>
</table>

√ = Recommendation applies to program
- Revise licensing and certification laws that create unnecessarily inconsistent restrictions on what services can be delivered by certain workers

Include consumers in the process of designing services through consumer advisory bodies and by using quality improvement activities to seek consumer input into design and improvement of services

Include consumers in defining and measuring quality

Provide consumers with low barrier methods (e.g., hotline) for reporting complaints, opportunities for improvement; ensure linked to QA/QI functions

<table>
<thead>
<tr>
<th>CD-PAS MaineCare State Plan</th>
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<tbody>
<tr>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>✓</td>
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<td>✓</td>
</tr>
</tbody>
</table>

√ = Recommendation applies to program
# Increasing Consumer Choice

Consumer choice is defined as a set of alternatives from which a consumer selects a preferred option. The box below identifies a range of different types of choice an individual might exercise in accessing personal assistance services.

## Types of Choices

**Choice of programs.** In some cases, a person might be eligible for more than one program but their needs are better served in one program than the other. For example, a person with mental retardation who also has medical needs might choose between a program specializing in serving persons with mental retardation or a program with special expertise in addressing medical needs. Consumers might also have a choice between programs offering a more traditional agency-based approach to providing services, while some might prefer a program that offers more independence (with the increased responsibility that goes with increased independence).

**Choice of access point.** A consumer might have a choice of ways to access services, whether the choice be between state regional offices or community providers.

**Choice of service coordinator supports.** A consumer might have a choice among service coordination providers or brokers, and the functions provided. The service coordinator and service broker might offer different levels of support in planning services, ongoing evaluation of services, etc.

**Choice of services.** Within a program, a consumer might have a choice between PAS, alternatives to PAS (e.g., assistive technology), or cash.

**Choice of providers.** A consumer might have a choice among agency providers and among workers providing direct service. For persons who employ their own workers, support services can make that option more attractive, including fiscal and employer agent services, employer support, counseling and training, worker registries, and emergency back-up supports.

## Consumer Choice and Consumer Control

As discussed previously, consumer control and consumer choice are intertwined. Consumer control is premised upon the availability of consumer choice. At the same time, the existence of consumer control can minimize the need for some types of choice. For example, if a program offers a cash option, it may not be as important to offer a consumer a choice of programs, so long as the permitted use of the cash is broad enough to encompass different service types.

The availability of different kinds of choice can also minimize the need for other kinds of choice. A state can minimize the need for an array of programs by offering greater choice within programs. For example, a program might offer a continuum of service models, including agency-based services, consumer-directed services, or a cash option.
**Limits on Consumer Choice**

Like consumer “control,” consumer choice is also limited. For example, consumer choice is limited by a rural state’s inability to support multiple provider options, the limited cost effectiveness of duplicative overhead associated with multiple programs or providers, the State’s interest in maximizing equity by developing standardized processes for allocating resources, etc. Choice is also bounded by limits on the consumer’s ability to make informed choices when there are too many options.

Some of the factors limiting consumer choice are described in more detail in the box below.

<table>
<thead>
<tr>
<th>Limits on Consumer Choice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Generally.</strong> The availability and accessibility of information about choices; the limit on a consumer’s ability to take in information about options; the relationship to other choices (e.g., the disincentive to work if income threatens eligibility for PAS; the requirement to accept case management as part of the service package).</td>
</tr>
<tr>
<td><strong>Across programs (specialty/type of disability; philosophical approach)</strong> State’s &amp; providers’ ability to support multiple programs.</td>
</tr>
<tr>
<td><strong>Across entry points.</strong> The State’s ability to support multiple access points; the State’s interest in standardizing eligibility determination and budgeting process; federal restrictions on how eligibility is determined.</td>
</tr>
<tr>
<td><strong>Support from service coordinator or broker.</strong> Training and role definition for service coordinators; availability and role definition for service brokers; accountability functions (e.g., QA monitoring).</td>
</tr>
<tr>
<td><strong>Services.</strong> The availability of a service broker to assist a consumer in identifying and selecting appropriate options; the availability of service options, especially in rural areas; state and federal approval of alternative uses.</td>
</tr>
<tr>
<td><strong>Where, when, and how services delivered.</strong> Program constraints on choice; provider or worker liability or licensing constraints; provider policy; provider or worker training.</td>
</tr>
<tr>
<td><strong>Providers and workers.</strong> For providers, the reimbursement rate, and a rural state’s ability to sustain a choice of multiple provider agencies, with duplicative administrative costs. For workers, the existence of a competitive reimbursement rate and career path and other factors impacting worker supply; the menu of employer supports (fiscal and employer agent services, worker registry, consumer training); the availability of emergency back-up, etc.</td>
</tr>
</tbody>
</table>

In some cases, consumers might be offered a choice of service models, but the models offered do not provide a meaningful choice. For example, the choice between consumer-directed and agency-based services might not be meaningful for some consumers, in the absence of emergency back up services, a support broker to assist with finding services, or a fiscal/employer agent to manage payroll.

For some people a choice between specialized programs can mean choosing between programs neither of which completely meet their needs. A person with mental retardation with significant...
medical needs might end up getting his or her medical needs met but might not have access to specialized personal support services.

**Recommendations for Increasing Consumer Choice**

To see how these recommendations apply across PAS programs, see the summary matrix, *RECOMMENDATIONS FOR INCREASING CONSUMER CHOICE OVER PAS*, at the end of this section.

1. *Provide a range of service models offering consumers choice over how much control to exercise.* Some individuals will need no help finding and scheduling workers. Others will not feel comfortable in that role. Some individuals will have family and friends in close proximity to provide emergency back-up, while others will not have a natural support system. To satisfy the individual needs of different consumers, a flexible array of service options would allow consumers to select the level of support best for them. Options might include the option to access a service broker to assist with finding services, providing assistance with emergency back-up services, a fiscal/employer agent to manage payroll, and offering agency-based services to those who have no interest in consumer directed services.

2. *Minimize the need to choose among PAS programs by increasing flexibility within programs and coordination across programs.* Cross-training direct support workers to provide personal assistance, behavioral and habilitative services would support greater flexibility within a program. Where needed services are not available within a program, better coordination in the service planning and delivery across programs, would minimize the need for an “either/or” choice between specialized services offered through alternative PAS programs.

3. *Support meaningful choice among workers by paying competitive wage rates and benefits.* Currently, waiting lists for staffing suggest that many consumers do not have meaningful choice among workers. While research has not been able to definitively link wages and benefits to the ability to attract and retain workers, common sense suggests that, where all else is equal, jobs offering higher pay and benefits are more attractive. While not losing sight of other factors impacting worker availability, the State should continue its efforts to increase worker pay and access to health benefits.29

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29 Under a Workforce Demonstration grant, also funded through the Centers for Medicare and Medicaid Services, the State is exploring the feasibility of increasing access to health insurance benefits for direct care workers through *Dirigo Health*. 

Muskie School of Public Service

*Access, Choice and Control*
## Recommendations for Increasing Consumer Choice over PAS

### Summary Matrix

<table>
<thead>
<tr>
<th></th>
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<th>Homemaker Services General Fund</th>
<th>Personal Support Services MR Waiver</th>
<th>PCS MaineCare State Plan (Children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide a range of service models by developing a menu of support services (e.g., fiscal/employer agent, worker registry, emergency back-up, support broker services, etc.) to allow consumers to select level of control they wish to exercise</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<td>√</td>
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<td>√</td>
</tr>
<tr>
<td>Minimize need for choice among programs • Increase coordination in service planning and delivery across programs • Increase cross-training for providers and workers across programs</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
</tr>
<tr>
<td>Support meaningful choice among workers by paying competitive wage rates and benefits</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td>√</td>
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<td>√</td>
</tr>
</tbody>
</table>

√ = Recommendation applies to program.
The following policies were reviewed for this report. Some were excluded from the comparative analysis because they were not “personal assistance” as defined for this report (e.g., they focused more on skill development than assistance) or it was determined the service was short term or targeted for a very specific use. However, much of the analysis and recommendations may still apply to those services that were excluded.

### Written Policies Reviewed

<table>
<thead>
<tr>
<th>Written Policies Reviewed</th>
<th>Included in Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>From the MaineCare Benefits Manual (10-144 CMR Chapter 101)</em></td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 12 (Consumer Directed Attendant Services): Medicaid State Plan</td>
<td>✓</td>
</tr>
<tr>
<td>consumer directed personal assistance services.</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 17 (Community Support Services): Medicaid State Plan, daily</td>
<td></td>
</tr>
<tr>
<td>living supports for adults with serious mental illness.</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 19 (Home and Community-Based Benefits for the Elderly and Adults with</td>
<td></td>
</tr>
<tr>
<td>Disabilities): agency-based services for elders and adults.</td>
<td>✓</td>
</tr>
<tr>
<td>Chapter II, Section 21 (Home and Community-Based Waiver Services for Members with</td>
<td>✓</td>
</tr>
<tr>
<td>Mental Retardation): personal support for persons with mental retardation.</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 22 (Home and Community Benefits for the Physically Disabled):</td>
<td>✓</td>
</tr>
<tr>
<td>waiver offering consumer-directed PAS for adults</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 40 (Home Health Services): includes home health aide and certified</td>
<td></td>
</tr>
<tr>
<td>nursing assistant services for short term home health needs.</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 65 (Mental Health Services): includes children’s behavioral health</td>
<td></td>
</tr>
<tr>
<td>services (skill development).</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 94 (Prevention, Health Promotion, and Optional Treatment Services)</td>
<td></td>
</tr>
<tr>
<td>Chapter II, Section 96 (Private Duty Nursing and Personal Care Services): Medicaid</td>
<td>✓</td>
</tr>
<tr>
<td>State Plan, services for elders, adults and children; with consumer direction option.</td>
<td></td>
</tr>
<tr>
<td><em>From the Bureau of Elder and Adult Services Policy Manual (10-149 CMR Chapter 5)</em></td>
<td></td>
</tr>
<tr>
<td>Section 63 (In-Home and Community Support Services for Elderly and Other Adults):</td>
<td>✓</td>
</tr>
<tr>
<td>state funded agency-based services for elders and adults, with consumer-directed option.</td>
<td></td>
</tr>
<tr>
<td>Section 69 (BEAS Administered Homemaker Services): state funded, agency-based homemaker</td>
<td>✓</td>
</tr>
<tr>
<td>services for elders and adults, with consumer-directed option.</td>
<td></td>
</tr>
<tr>
<td><em>From the Bureau of Rehabilitative Services (12-152 CMR)</em></td>
<td></td>
</tr>
<tr>
<td>Chapter 8 (Consumer-directed Personal Care Assistance Services): state funded for</td>
<td>✓</td>
</tr>
<tr>
<td>adults.</td>
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</tbody>
</table>
### Glossary

**Alpha One**
The Assessing Service Agency and Home Care Coordinating Agency responsible for determining eligibility, creating the service plan, and for assisting with implementation of the service plan for persons receiving consumer-directed PAS services for adults with disabilities.

**Assessing Service Agency (ASA)**
The party responsible for determining eligibility for personal assistance services administered through BEAS.

**BEAS**
The Bureau of Elder and Adult Services, within the Department of Human Services. BEAS administers the long term care services for elders and adults with disabilities.

**BMS**
The Bureau of Medical Services, within the Department of Human Services. MaineCare is the state and federal partnership that pays for medical and long-term care services for people who meet the eligibility criteria for low income or medical need. BMS sets policy for MaineCare services, pays claims, and monitors the quality of service and providers. BMS coordinates its functions with other state agencies responsible for administering certain services funded through MaineCare.

**BRS**
The Bureau of Rehabilitation Services, within the Department of Labor. BRS administers the state funded consumer directed personal assistance programs, the independent living program and the vocational rehabilitation program.

**Certified Nursing Assistants (CNA)**
A certified nursing assistant can provide home health services through a home health agency. A CNA must be listed on the CNA registry and must have 150 hours of training.

**Daily Living Supports**
Offered under MaineCare Community Support Services, daily living supports are in home services available to persons with severe and disabling mental illness. Daily living supports include personal supervision and therapeutic support to develop and maintain daily living skills.

**Direct Support Professional**
The term used for the direct care worker providing personal support services to persons with mental retardation under the MR waiver.

**Elder Independence of Maine (EIM)**
The Home Care Coordinating Agency for services administered by BEAS.

**Goold Health Systems**
The Assessing Service Agency responsible for determining eligibility for long term care services offered through BEAS.

**Home Care Coordinating Agency (HCCA)**
The agency responsible for assisting with implementation of a service plan for persons accessing services through programs administered by BEAS. The scope of assistance will vary with the program.

**Home Health Aide (HHA)**
A home health aide provides home health services through a home health agency. A home health aide must be registered on the CNA registry, must have 150 hours of CNA training, and must have had the home health agency orientation.
**Home and Community-Based Services (HCBS) Waiver**

States may apply for an HCBS waiver that provides different services under different rules than allowed under the state plan. For example, under Maine’s waivers, certain community-based services are covered that are not allowed under the state plan, the income and asset tests are changed, and the number of people that can be served under the waiver is limited by available funding, even if more people are eligible for waiver services. Waivers are initially approved for three years and may be renewed at five-year intervals. A state must document that there are safeguards in place to protect the health and welfare of beneficiaries. Every year, a state must demonstrate to CMS that the cost of providing the home and community services does not exceed the average cost of care for the people served in an institution. By federal law, eligibility for the home and community based waiver services is limited to only those whose needs require institutional level services.

<table>
<thead>
<tr>
<th><strong>Homemaker Services</strong></th>
<th>Homemaker services are a subcategory of personal assistance services and include assistance with routine housekeeping, including light cleaning, meal preparation, grocery shopping, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICF-MR</strong></td>
<td>Intermediate care facility for persons with mental retardation. An ICF-MR is considered to be a nursing facility for the purpose of determining eligibility for the MR waiver.</td>
</tr>
<tr>
<td><strong>Individual Service Coordinator</strong></td>
<td>State employee in regional DHHS offices responsible for coordinating services for persons with mental retardation.</td>
</tr>
<tr>
<td><strong>MaineCare</strong></td>
<td>The name applied to the federally governed Medicaid program in Maine.</td>
</tr>
<tr>
<td><strong>MED</strong></td>
<td>Medical Eligibility Determination form, used to determine eligibility for personal assistance services offered through BEAS.</td>
</tr>
<tr>
<td><strong>MR Services</strong></td>
<td>MR Services administers the waiver program for persons with mental retardation and autism, the community support services for persons with mental illness and services for children with pervasive developmental disorders, mental retardation or autism, emotional disturbance, behavioral disorders, mental illness, etc.</td>
</tr>
<tr>
<td><strong>MR Waiver</strong></td>
<td>The HCBS waiver for persons with mental retardation, governed under MaineCare Benefits Manual, Chapter II, Section 21.</td>
</tr>
<tr>
<td><strong>Personal Care Services</strong></td>
<td>The term used to describe services provided to elders and adults in certain programs administered by BEAS.</td>
</tr>
<tr>
<td><strong>Personal Support Specialist</strong></td>
<td>The term used for direct care workers providing in-home services through certain BEAS-administered programs. An agency-based personal support specialist must have 40 hours of training.</td>
</tr>
<tr>
<td><strong>Personal Assistance Services (PAS)</strong></td>
<td>Any service that compensates for a disability by delegating to another individual a task which a person with a disability would perform him or herself, but for the disability. Included in this category are personal care services provided to elders, adults and children (agency-based and consumer-directed) and personal support services provided to persons with mental retardation.</td>
</tr>
<tr>
<td><strong>Personal Support Services</strong></td>
<td>Personal support services are provided to persons with mental retardation under the MR waiver and include assistance with daily living and social supports.</td>
</tr>
</tbody>
</table>