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**Report of the Working Group
on Consumer Direction in Maine's Long-Term
Supportive Services System**

**A Review, Study and Recommendations
for the Commissioners of Health and Human Services
and Labor
and the Joint Standing Committees on Health and
Human Services and Labor**

January 1, 2005

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Report of the Working Group
on Consumer Direction in Maine's Long-term
Supportive Services System

Table of Contents

| | |
|--|---|
| Executive Summary | I |
| Introduction and Charge..... | 1 |
| Working Group Membership and Process..... | 2 |
| Maine's Long-term Supportive Services System – A Snapshot..... | 2 |
| Foundational Principles..... | 2 |
| New Approaches in Long-term Supportive Services | |
| <i>Expanding Consumer Directed Alternatives</i> | 3 |
| <i>Surrogacy – Alternative Decision Making Models</i> | 4 |
| <i>Enhancing the “Intake” Process</i> | 4 |
| Providing Direct Care Workers a Livable Wage..... | 5 |

Executive Summary

Report from the Working Group on Consumer Direction in Maine's Long-Term Supportive Services System

This report is the work of a group established pursuant to PL 03 Chapter 673. Sections WW-4 and WW-5.3. Section WW-4 required the Department of Human Services to convene a group of interested consumers, providers of personal care services, a representative of the Maine Independent Living Center, organizations representing personal assistants, advocates and department personnel to identify strategies for improving services and to develop an intake system for consumers seeking assistance. Section WW5.3 required the Department of Labor and the Department of Human Services to jointly review the departments' programs for consumer-directed personal care assistance services. The departments were to conduct this review with the participation of consumers and other interested parties, including organizations representing the interests of persons likely to use a surrogate and organizations representing personal care assistants, and report to the Committee on Health and Human Services by January 1, 2005. The report was to include recommendations on:

- guiding principles for expanding eligibility to include consumers who use a surrogate to perform management tasks the consumer would otherwise perform, and
- actions to encourage the use of consumer-directed options by promoting consideration of the use of surrogacy as the choice for appropriate consumers.

The recommendations of this work group reflect a broad consensus among stakeholders interested in the expansion of consumer directed alternatives throughout Maine's long-term supportive services system. The goal of expanding consumer direction reflects a shared desire to maximize consumer choice, promote independent living, and encourage personal and family responsibility. Implementing the recommendations of this Working Group can offer the benefits of consumer direction to a much broader population of existing consumers currently utilizing the state's long-term supportive services system.

Foundational Principles

Changes in Maine's long-term supportive services system should be guided by these principles:

- System should be flexible, agile, and transparent.
- Level of service should be based on function of the consumer rather than some other determination such as diagnosis or age.
- There should be a seamless continuum of services from CD-PAS to agency-based services to facility-based services, and consumer choice should be maximized in this system.

- There is a need to move away from the medical model – these programs should be about life, not just medical management. At the same time, there needs to be recognition that the services exist within the context of funding for medical services through Medicaid
- Consumer direction should be expanded using surrogacy for all populations based on function.
- Programs should be cost-efficient and accountable.
- Direct service workers should receive a livable wage, benefits and protections.

Surrogacy – Alternative Decision Making Models

One important avenue for the expansion of consumer directed alternatives is consumer utilization of alternative decision makers, or surrogates. While there are a variety of models to support alternative decision making in Maine’s long term supportive services system, at a minimum, the Working Group agreed to the following elements:

First, a consumer who has a guardian may participate in consumer directed programs provided the guardian is willing to meet all the requirements for participation in the program.

Second, a consumer with or without cognitive capacity, as currently defined by rules, may participate in the consumer directed programs by creating a legal relationship, such as an agent under a power of attorney, who is willing to meet all the requirements for participation in the program.

Enhancing “Intake” for the Long-Term Supportive Services System

The Working Group endorsed the general concept of an intake system that has “no wrong door” and further agreed:

A concerted effort should be made to provide Maine citizens with up to date, accurate, easily understood information that can guide them to the resources and services that may be available to support their choice regarding the delivery of long-term supportive services. The system should accommodate change in consumer choice.

Providing Direct Care Workers a Livable Wage

Essential to the successful operation of the long-term supportive services system, and particularly consumer directed programs, is the ability to offer a livable wage to direct care workers. While this is the central focus of efforts being made by other coalitions and stakeholder groups, the Working Group recognized that a key to quality services is the ability to recruit and retain workers with competitive wages and benefits. Overall program design must take into account the necessity of a livable wage in order to have a system that provides a sustainable employment alternative.

Report from the Working Group on Consumer Direction in Maine's Long Term Supportive Services System

Introduction and Charge

Public Law 03 Chapter 673, the final supplemental appropriations and allocations act of the Second Special Session of the 121st Maine Legislature charged the Departments of Health and Human Services and Labor with reviewing, studying and making recommendations about certain aspects of consumer directed programs within Maine's long-term supportive services system.

The charges to the departments as contained within the act follow:

Sec. WW-4.

4. Working group. The Department of Human Services shall convene a working group of interested consumers, providers of personal care services, a representative of the Maine Independent Living Center, organizations representing personal assistants, advocates and department personnel to identify strategies for improving services and to develop an intake system for consumers seeking assistance.

Sec. WW-5.

3. Joint review and report. The Department of Labor and the Department of Human Services shall jointly review the departments' programs for consumer-directed personal care assistance services. The review must include participation from consumers and other interested parties, including organizations representing the interests of persons likely to use a surrogate and organizations representing personal care assistants. The departments shall report to the joint standing committee of the Legislature having jurisdiction over labor matters and the joint standing committee of the Legislature having jurisdiction over health and human services matters by January 1, 2005 on the results of their review and the recommendations of the departments.

The report of the departments must include recommendations on the following issues:

- A. Guiding principles for expanding eligibility to include consumers who use a surrogate to perform management tasks the consumer would otherwise perform; and
- B. Actions to encourage the use of consumer-directed options by promoting consideration of the use of surrogacy as the choice for appropriate consumers.

The departments may not expand the programs to include consumers who use surrogates to perform management tasks the consumers would otherwise perform themselves until the report required in this subsection has been submitted and the

per capita costs of the programs are at levels that allow the programs to operate within legislative appropriations and allocations.

Working Group Membership and Process

Pursuant to the act, the Bureau of Elder and Adult Services convened the Working Group. The membership and participation was relatively fluid, with the group expanding or contracting based on functions such as the topic under discussion. A list of those who attended one or more meetings is attached as an Appendix

The Working Group met a total of thirteen times beginning in August 2004.

Given the fluid nature of the membership of this group, the process was consensus-based and informal rather than based on a series of definitive votes. As a result, this final product reflects the general nature of the group and the range of interests represented. Presented here are more policy directions than specific program recommendations. The result is intended to be one element in the broader public policy formulation by Baldacci administration officials. This is significant particularly in the context of other committees and working groups, such as the Direct Care Workers Coalition, the Working Group on the Mental Retardation Waiver, and the Commissioner's Task Force advising him on the reorganization of the Department of Health and Human Services.

Maine's Long-Term Supportive Services System – A Snapshot

The details about funding source, eligibility for, services included, cost caps and other information are included in the matrix of Maine's long-term supportive services system attached as Appendix Two.

Foundational Principles

Early in the Working Group process, following extended discussion, a consensus developed around a set of Foundational Principles. These principles are:

- System should be flexible, agile, and transparent.
- Level of service should be based on function of the consumer rather than some other determination such as diagnosis or age.
- There should be a seamless continuum of services from CD-PAS to agency based services to facility-based services, and consumer choice should be maximized in this system.
- There is a need to move away from the medical model – these programs should be about life, not just medical management. At the same time, there needs to be recognition that the services exist within the context of funding for medical services through Medicaid

- Consumer direction should be expanded using surrogacy for all populations based on function.
- Programs should be cost-efficient and accountable.
- Direct service workers should receive a livable wage, benefits and protections.

New Approaches in Long-Term Supportive Services

Expanding Consumer Directed Alternatives

Consumer direction enhances choice and self-determination for the participants in Maine's long-term supportive services system.

The Working Group examined many of the existing programs within Maine's long-term supportive services, identifying both current applications of consumer directed alternatives, as well as areas where consumer direction could be expanded directly or with the use of a surrogate decision-maker. This cursory examination indicated federal law places few restrictions on the expansion of consumer direction. Similarly, the present state statutory framework allows for greater utilization of consumer directed options.

The recommendations of the Working Group can be implemented by the Departments adopting new rules.

In addition to expanding the availability of consumer directed alternatives within the system through systematic rule changes, the departments must improve how they informs consumers about their choices within the system. Informed choice, based on as complete an understanding as possible about alternatives within the system, depends upon the quality of information provided to consumers and/or their agents.

In order to expand access to consumer directed alternatives, the system must make a concerted effort to educate, inform, and market alternatives to consumers. This will be an ongoing task in delivering these programs.

There was no clear consensus within the Working Group regarding other techniques that could be employed. Some of the topics discussed include:

- Leaving the system as is, with improved information regarding consumer directed choices.
- Consumer direction as the system standard. People who meet the qualifications for consumer direction should be directed to the program.
- Providing incentives for consumers to select consumer direction over other models.

Surrogacy – Alternative Decisions Making Models

One key strategy for the expansion of consumer direction within the long-term supportive services system is the ability of a consumer to utilize the services of an unpaid agent, commonly referred to as a “surrogate,” to assist with the management tasks associated with these consumer directed services.

Utilization of such agents or surrogates could be made more widely available in many cases by amending existing rules governing the programs within the long-term supportive services system. Depending upon the functional capacity of the individual consumer, these agents may act either in an ongoing, or intermittent fashion.

The Working Group concluded that, where appropriate, the rules governing programs within the long term supportive services system should be modified to include the use of surrogates or agents. Specifically, the Working Group consensus was:

First, a consumer who has a guardian may participate in consumer directed programs provided the guardian is willing to meet all the requirements for participation in the program.

Second, a consumer with or without cognitive capacity, as currently defined by rules, may participate in the consumer directed programs by creating a legal relationship, such as an agent under a power of attorney, who is willing to meet all the requirements for participation in the program.

Enhancing the “Intake” Process

Intake is the initial point of contact for people entering the state funded long-term supportive services system. The Working Group discussed and embraced the central commitment to the concept of “No wrong door.” Consumers and their families should be able to get good information without being “run around.” People should be able to be revisit choices periodically based on changes in their lives – physical condition, family situation, or aspirations.

In reviewing the intake process, there are four primary questions that will assist consumers in exercising their informed choice regarding the long-term supportive services system. The order in which these questions are asked may also have a direct bearing on outcomes. Here are the questions:

- Would you like to consider managing your own services?
- Are you capable of directing (by yourself or with a surrogate) your own services?
- What are your aspirations (What do you want to do with your life)?
- What are you capable of doing? What are your functional limitations?

The Working Group was able to agree on a major program/policy approach:

A concerted effort should be made to provide Maine citizens with up to date, accurate, easily understood information that can guide them to the resources and services that are available to support their choice regarding the delivery of long-term supportive services. The system should be able to accommodate requests from consumers for changes in how they are receiving services.

Providing Direct Care Workers a Livable Wage

Essential to the successful operation of the long-term supportive services system, and particularly consumer directed programs, is the ability to offer a livable wage to direct care workers. While national and state data suggests a high level of satisfaction among both direct care workers and consumers with these consumer directed alternatives, attention must be paid to providing a livable wage to direct care workers.

While this is a central focus of efforts being made by other coalitions and stakeholder groups, the Working Group recognizes that a key to quality services is the ability to recruit and retain workers with relatively competitive wages and benefits. Overall program design must take into account the necessity of a livable wage in order to have a system that provides a sustainable employment alternative.

There is a need to address job classification, adequate wages and benefits across all programs in order to attract and retain personnel. At this time the wage rates are not adequate, the low wages and variable work hours put the profession into the low income and poverty level status. We need to build and support the workforce in order to support individuals with disabilities and elders in all their care and service settings. The CD PAS, home and community-based programs support the services in the least costly manner when compared to nursing home and residential facilities. There is a growing need for home-based services. The Maine Department of Labor lists health aides as one of the top 5 jobs expected to grow in the next 10 years.

Appendix One: Working Group Membership

The following individuals – including consumers, direct care workers, providers, advocates, representatives from labor organizations, representatives from Maine's Independent Living center, and staff from the Maine Department of Health and Human Services and the Maine Department of Labor – attended one or more meetings.

Earl Babcock, DHHS, Adult Mental Retardation Services
John Babcock, Consumer
Mollie Baldwin, DHHS, Bureau of Elder and Adult Services
Robin Brown, Goold Health Systems Assessing Services,
Catherine Cobb, DHHS, Bureau of Elder and Adult Services
Darleen Crosby,
Era Decker, Personal Assistant
Les Decker, Consumer
Leo Delicata, Legal Services for the Elderly, Inc.
Mary Lou Dyer, Maine Association of Community Service Providers
Dennis Fitzgibbons, Alpha One,
Betty Forsythe, DHHS Bureau of Elder and Adult Services
Joyce Gagnon, Personal Assistant
Jane Gallivan, DHHS, Adult Mental Retardation Services
Elizabeth Gattine, DHHS, Bureau of Elder and Adult Services
Christine Gianopoulos, DHHS, Bureau of Medical Services
Jay Hardy, Alpha One
Bill Hughes, DHHS, Adult Mental Retardation Services
Lisa Harvey-McPherson, Home Care Alliance of Maine
Pam Jones, Personal Assistant
David Knight, Personal Assistant
Deborah Knight, Consumer
Peter Leeman, Consumer
Donald McCaslin, Consumer
Matt McDonald, Maine State Employees Association
Kim Moody, Disability Rights Center
Kathryn Pears, Alzheimer's Association
Jim Pierce, Provider
Peter Rice, Disability Rights Center
Susan Rovillard, Home Care for Maine, Director
Elise Scala, Muskie School of Public Service
Dennis Stubbs, Consumer
Cynthia Sudheimer, Consumer
Marina Thibeau, DHHS
Catherine Valcourt, Long-term Care Ombudsman Program
Patten Williams, DOL, Bureau of Rehabilitation Services

| Program | Fund Source | Age Limit | Income/ assets | Assessing Agency | Medical Criteria | Services | Care Coordination, Authorization & Monitoring | Program cost Cap | Copay/ cost sharing |
|--|----------------|-----------------------|---|---|---|--|--|---|---------------------|
| Medicare | Federal | 65+ (unless disabled) | NA | Home health agency | Skilled need, Homebound MD order | RN, LPN, HHA, PT, OT, ST, MSW | Home health agency | Up to 28 hours/week | |
| MaineCare | | | | | | | | | |
| Home Health SEC:40 | State/ Federal | none | 100% poverty, Assets: 2,000/1, 3,000/2 \$8,000/1 \$12,000/2 allowed exclusions > than asset limit above | Home health agency Assessing Services Agency | Based on skilled nursing or therapy need at least twice monthly MD ordered and certified outpatient contraindicated Assessment, management, teach & train limited to 120 days | RN, LPN, HHA, PT, OT, ST, MSW, Pyschiatric medication visits | Home health agency or prior authorization when required | None | \$5/month |
| Private Duty Nursing/ Personal Care Services SEC: 96 | State/ Federal | none | | Home health agency | Level IV: NF eligible only for age 21 and under Level I, II & III, VIII < less age 21 (See definitions below) | RN, LPN, HHA, PCA (See definitions below) | Home health agency | 100% NF for age < 21 (\$3133) | |
| | | | | Assessing Services Agency | Level I: limited assistance and 1 person physical support in 2 of 7ADLs or cueing in 4 ADLs or limited assist & 1 person physical support in 1ADL & physical assistance w/ 2 IADLS or a nursing need once a month | RN or HHA, CNA, PCA | Elder Independence of Maine | Level I (\$750/month) | |
| | | | | | Level II: Monthly nursing need + limited assistance and 1 person physical support in 2 ADLs or cueing in 4 ADLs | RN, LPN, HHA, CNA, PCA | | Level II (\$950/month) | |
| | | | | | Level III: Monthly nursing need and limited assistance and 1 person physical support in two of bed mobility, transfer, locomtion, eating, toileting | RN, LPN, HHA, CNA, PCA | | Level III (\$1,550/month) | |
| | | | | | Level V: ventilator dependent or 24 hour care in 3 areas of skilled nursing Level VIII-Nursing services only for MR, Phy Dis, CDAS, Assisted Living & Adult Family Care Homes | RN, LPN, HHA, CNA, PCA RN only | | Level V (\$20,682/mo) Level VIII-\$750/month | |
| Adult Day health SEC: 26 | State/ Federal | 18+ | Home health agency Day Care provider or Assessing Services Agency | Venipuncture-blood draw Psychiatric medication services-prefill of medications Level I-Limited assistance and 1 person physical support in 2 of 7 ADLs or cueing in 4 ADLs Level II- Limited assistance and 1 person physical support in 2 of 5 late loss ADLs of meets cognitive or behavior threshold Level III- meets NF medical eligibility criteria | RN/LPN Psych RN/RN Monitor health care, nursing, rehab counseling, exercise, health promotion | Home health agency Day care provider | Level VI-\$2,400/yr Level VII-\$12,000/yr Level I-16 hrs /wk Level II-24 hrs /wk Level III-40 hrs/wk | | |
| Consumer directed PA SEC: 12 | State/ Federal | 18+ | Assessing Services Agency | Level I-Limited assistance and 1 person physical support in 2 ADLs and cognitively capable to self direct Level II- Limited assistance and 1 person physical support in 3 of 5 late loss ADLs & cognitively capable to self direct Level III-Extensive assistance & one person physical assist in 2 of 5 late loss ADLs & limited assist in 2 of 7ADLs & cognitively capable to self direct | Personal care assistance Skills training included in PCA rate | Alpha One | Level I-\$474/month Level II-\$710/month Level III-\$1105/month | | |

| MaineCare Benefits (HCB Waivers) | | | | | | | | | |
|--|-------------------------|-----------------------------------|--|--|---|--|---|--|--|
| Physically Disabled SEC: 22 | State/ Federal | 18 + | 224% poverty (\$1737/month) Assets \$2,000/1 3,000/2 | Assessing Services Agency | NF eligible and cognitively capable to self direct | Case Mgmt with Skills training and consumer directed PCAs | Alpha One | 100% NF aggregate Limit of 86.25 hr/week | Countable income greater than 125% of poverty |
| Elderly & Adults with Disabilities SEC: 19 | State/ Federal | 18-59 60-64 disabled 65+ | \$8,000/1 \$12,000/2 allowed excels > than asset limit above | Assessing Services Agency | NF eligible | Case Mgmt, RN, HHA, CNA, PT, OT, ST, PCA, Hmkr, ADH, ER, MH, Trans, respite | Elder Independence of Maine | 100% NF (\$4341) | Countable income greater than 125% of poverty |
| Program | Fund Source | Age Limit | Income/ assets | Assessing Agency | Medical Criteria | Services | Care Coordination, Auth & Monitor | Program cost Cap | Copay/cost sharing |
| Home Based Care | | | | | | | | | |
| Phys/disabled Consumer directed Chapter 8-DOL | State | 18+ | no upper limit | Assessing Services agency | Limited assistance and 1 person physical support in 2 of 7ADLs and cognitively capable of self direction | Personal care assistance Skills training included in PCA rate | Alpha One | Up to 30 hours per week plus nighttime hours < 10 hours /week for specific ADLS | 4% of monthly income + 3% of assets > \$30,000 |
| Elderly and Other Adults BEAS: 63 | State | 18+ | Assets less <\$50,000 for 1, <\$75,000 for 2 | Assessing Services Agency | Minimum threshold: Total of 3 - w/min of 1 ADL (ADL, IADLs, nursing service) or cueing in 4 ADLs | Case Mgmt, RN, HHA, CNA, PT, OT, ST, PCA, Hmkr, ADH, ER, MH, Transportation, respite | Elder Independence of Maine | Level I= \$900 Level II=\$ 1,100 Level III=\$ 1,675 Level IV=80% NF (\$2908/month) | 4% of monthly income + 3% of assets > \$15,000 |
| BEAS Homemaker BEAS 69 | State | 21+ | Assets less <\$50,000 for 1, <\$75,000 for 2 | Homemaker provider or Assessing Services Agency | Needs assistance, done with help in 3 IADLs: main meal prep, routine cleaning, grocery shopping or laundry or limited assistance and one person physical support in 1 ADL & 1 IADLs from above | Homemaking, chore, grocery shopping, laundry, incidental personal care, transportation | Home Resources of Maine or Aroostook Home Health Services | Maximum ten hours per month, currently modified to 6 hours/month | 20% of cost of services |
| Alzheimer's Support BEAS 68 | State and Federal | 18+ | Assets less <\$50,000 for 1, <\$75,000 for 2 | Area Agency on Aging BEAS | Need based | In-home or institutional respite Adult day care respite | Area Agencies on Aging BEAS | up to \$3,800 per year | 20% of cost of service |
| Residential Care Facilities Section 97 | State and Federal | 18+ | Gross income limit varies with facility rate \$2000 in assets | Residential care provider | Needs shelter and support | Room & board, medical, remedial services | Residential Care provider | Difference between net monthly income & MaineCare reimbursement rate | Depends on income. Generally, residents can keep up to \$70/month |
| Independent Housing w/Svcs Section 62 | State | 18+ | Assets less <\$50,000 for 1, <\$75,000 for 2 | IHSP provider | 3 IADLs where assistance and done with help required, or limited assistance in 1 ADL & 2 IADLs or limited assistance in 2 ADLs. | Service coordination, chore services, 1 meal per day | IHSP provider | Based on needs of consumer | 20% cost of services |
| Adult Day Services Section 61 | State | 18+ | Assets less <\$50,000 for 1, <\$75,000 for 2 | Day Care provider or Assessing Services Agency | Limited assistance and 1 person physical support in 1 ADL or cueing in 4 ADLs | Monitor health care, nursing, rehab counseling, exercise, health promotion | Day care provider | Attend minimum 4 hours weekly | 20% cost of services |
| Adult Family Care Homes SEC: 2 | State and Federal | 18+ | \$ <\$16 gross income, Assets < \$2,000 (incl up to \$8,000 of savings) | Adult Family Care Home | Completion of MDS-AL within 30 days of admission to have DHHS compute the member's classification group | Room & board, medical, remedial services | Adult Family Care Home Provider | Based on needs of resident | Depends on income. Generally, residents can keep up to \$70/month |