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Quality Indicators for Home and Community-based Services in Maine [Report]

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Quality Indicators for Home and Community-Based Services in Maine

- Older Adults and Adults with Disabilities
- Adults with Physical Disabilities - Who Self Direct
- Adults with Mental Retardation/Autism
This report was prepared under a Cooperative Agreement between Muskie School of Public Service and Maine Department of Health and Human Services. Sponsored by the Maine Department of Health and Human Services, with the participation of consumer groups, advocates, and other state agencies. The State of Maine does not discriminate on the basis of disability, race, color, creed, gender, age, or national origin in admission to, access to, or operations of its programs services or activities, or its hiring practices.

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Acknowledgements
This report was prepared as a collaborative effort of the home and community based service (HCBS) program agencies that administer and manage three of Maine’s HCBS Waivers: Older Adults and Adults with Disabilities, and Adults with Physical Disabilities who direct their own services; Adults with MR and Autism. The indicators that are highlighted in this report were identified as ones of importance and relevance by a Quality Technical Advisory Group (Quality TAG). The Quality TAG included representatives of consumers, advocates, providers, other stakeholders and policy makers.

The authors would like to thank all who participated in the development, review and final preparation of this report. Mollie Baldwin, from the Office of Elder Services, provided guidance and thoughtful comments on program descriptions and data presentation for the Older Adults and Adults with Disabilities Waiver and the Physically Disabled-consumer directed waiver. Jane Gallivan and David Goddu from the Office of Adults with Cognitive and Physical Disabilities Services provided important input and review of the Adults with MR/Autism program design and report presentation.

Finally, we would like to extend our appreciation to Christine Richards for her editing, layout and design of the final product.
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**Introduction**

**Population Groups**
- Older adults and adults with disabilities
- Physically disabled: consumer directed
- Adults with mental retardation and autism (MR/A)

**Definition: HCBS Waiver**

The term, HCBS Waiver, refers to the special approval that states receive from the Centers for Medicaid & Medicare (CMS) to design more flexible services to meet the individual needs of people in the community. Home and Community Based Service (HCBS) waivers provide services to people in the community who are eligible to be in an institution but prefer to receive services in their home or the community.

**Purpose**

The purpose of this report is to provide summary information on the performance of Maine’s home and community based care system. The data in this report can be used to identify areas where the system is working and people are satisfied with services and to identify areas where improvement may be needed. The data may also point to areas where further analysis or more information would be helpful. The data in the report represents baseline information. There are no absolute standards or norms against which the results can be compared. In some instances, it will be important to use the data as a basis for further discussion and inquiry in order to “interpret” or draw conclusions from the results. This is part of an ongoing quality improvement process.

**Background**

In 2001, the Maine Department of Health and Human Services received a three year grant from the U.S. Department of Health and Human Services to improve services for people with disabilities. The goal of the Quality component of the grant was to select a set of core quality indicators for home and community based services across population groups. These core indicators provide a way for consumers, policy makers and other stakeholders to routinely and systematically assess the overall performance of the home and community-based service system. The results of the core indicators also provide information that can be used to identify priority areas for quality improvement.

In 2003, the Maine Department of Health and Human Services received a three year grant to develop an inter-departmental approach to improving quality for people with disabilities in the community. One of the goals of the grant is to assess the performance of the HCBS system in Maine. Using the core indicators as a foundation, this report provides baseline information on key areas of focus for home and community based services in Maine.

**Population Groups**

This report focuses on three population groups who receive long term services and supports in their home:

- older adults and adults with disabilities
- physically disabled adults who self-direct their own services; and
- adults with mental retardation and autism

These are individuals who are eligible to be in an institution but prefer to receive services in their home or community. They receive services through the HCBS waiver.
A Quality Technical Advisory Group (TAG) was formed in 2002 to provide advice and guidance on the selection of a set of core indicators. Members of the Quality TAG included representatives of consumers, advocacy organizations, providers, other stakeholders and department staff responsible for Home and Community Based Services (HCBS). The Quality TAG identified a set of core quality indicators for each population group. These core indicators are called “dashboard indicators.”

This report is the result of a collaborative effort between the administering agencies for these HCBS waiver programs.

Dashboard Indicators
This report includes the core measures that were identified as “dashboard” indicators by the Quality TAG. The report is organized according to the major focus areas identified in the HCBS Quality Framework. In addition, Health Care Utilization has been added as an area of focus for purposes of this report.

For each focus area, the Quality TAG identified one to three dashboard indicators. Because the dashboard indicators are derived from a number of different sources, the report is organized such that the indicators for each HCBS waiver can be viewed individually. The only exception to this approach is the set of dashboard indicators that are derived from administrative claims data (see Health Care Utilization).

In addition, in some instances the indicators are reported for a group that may include more than just those individuals served by a particular waiver. This approach reflects the historical approach taken by the HCBS program area. For example, the Bureau of Elder and Adult Services conducts a survey of all people accessing LTC services and their satisfaction with the assessment process. This survey does not separately identify people who are served by the HCBS older adult waivers. The Bureau of Developmental Services conducts an annual survey of consumers and family members for people with mental retardation and autism. The survey has not separately identified “HCBS waiver” participants. Throughout the report, we identify the population for which the indicators are reported.

Organization of Report
The report is organized into chapters that correspond with the Focus Areas identified in the HCBS Quality Framework developed by the Centers for Medicare & Medicaid. Each chapter begins with a brief summary of the program design features for each HCBS Waiver program. The summary is followed by core measures for each population group. Because the data come from a number of different sources, care should be taken in making comparisons across program areas.

For ease of review, the reader may want to focus on one chapter at a time or may want to focus on one population group at a time.
Data Sources

Overview
The data for this report are derived from a variety of sources and for a number of different years.

Consumer Surveys:
Historically each HCBS program area has administered separate consumer surveys using different survey approaches. The survey methods have included:

- mail surveys which are completed by consumers and/or family members;
- in-home interviews with consumers;
- consumer surveys sent to and administered by providers; and
- family/guardian surveys

Medicaid and Medicare Claims Data
Many of the people served by HCBS Waiver programs are dually eligible for Medicaid and Medicare. For this reason, it is necessary to link Medicaid and Medicare claims data at the individual level in order to get a full picture of the utilization of services. The linked Medicare and Medicaid data were only available for the year 2000. Thus, the indicators derived from the linked Medicare and Medicaid data represent baseline data for which more current data will soon be available for comparison purposes. Results from the use of the linked Medicaid-Medicare data are provided in the Health Care Utilization section.

Administrative Data

MeCare Data
Other administrative data includes data from the MeCare long term care assessment system. This system includes demographic, cognitive, behavioral and other assessment level information for older adults and adults with disabilities who are seeking long term care services.

EIS Data
The Enterprise Information System provides core assessment, care planning and incident reporting information for people with MR/A.

Each of these data sources will be discussed in more detail below.
# Data Sources

## Consumer Surveys

**Older Adults and Adults with Disabilities**

The Bureau of Elder and Adult Services administers two surveys:

**Assessment Survey:**
- **Purpose:** To assess consumer satisfaction with the assessment process conducted by Goold Health Services.
- **Population surveyed:** All those who receive a Goold assessment. This includes all older adults and adults with disabilities who seek long term care services in Maine.
- **Method:** Mailed survey
- **Response rate:** The survey was sent to 2,242 people. Six-hundred and sixty-two people responded representing a 30% response rate.
- **Year:** Survey was mailed in the fall of 2003.

**Home Care Satisfaction Survey:**
- **Purpose:** To assess consumer satisfaction with care management and personal care services they are receiving provided by Elder Independence of Maine (EIM).
- **Population surveyed:** All older adults and adults with disabilities receiving any Medicaid or state funded HCBS services provided through EIM.
- **Method:** Mailed survey
- **Response rate:** Survey was mailed to 3,025 people, 51% responded (1,537 people).
- **Year:** Survey was mailed in the summer of 2004.

**Physically Disabled: Consumer Directed**

**The Participant Experience Survey for Consumer Direction**
- **Purpose:** To assess consumer’s experience directing their own services including satisfaction with training, hiring and managing workers and other aspects of the HCBS waiver for people with physical disabilities.
- **Population surveyed:** Criteria for being interviewed included being an active participant on the Consumer-Directed Waiver as of June 2004.
- **Method:** In-home survey conducted by the Survey Research Center at the University of Southern Maine.
- **Response rate:** A total of 265 potential participants were identified. And 67% (177 people) completed the survey.
- **Year:** The survey was conducted in 2004.

**Note: Calculation of Percentages**

Unless otherwise noted, the percentages that are shown in the report represent the proportion of people who answered the question with a “yes” answer. The denominator of this percentage includes all people who were asked the question including those who answered “unsure,” “don’t know,” or “no response.”

**Adults with MR/A**

**National Core Indicators:**

The Bureau of Developmental Services administers a consumer and a family survey developed as part of the National Core Indicators:

**Consumer Survey**
- **Purpose:** To identify and measure core indicators of performance of state developmental disabilities service systems.
- **Population surveyed:** Each year the Bureau of Developmental Services selects one third of adults receiving MR/A services (including waiver and non-waiver participants).
- **Method:** BDS staff train providers to conduct the interviews with consumers. Results are sent to BDS.
- **Response rate:** There were 417 respondents.
- **Year:** 2004

**Family Survey**
- **Purpose:** To provide information about the effectiveness of service systems in supporting families who have an adult family member with a developmental disability living at home with them.
- **Population:** All adults with MR case management services who live with their family.
- **Method:** Mailed survey.
- **Response Rate:** 637 surveys were mailed; 345 surveys were returned for a 54% response rate.
- **Year:** 2004

**Note: Calculation of Percentages**

In the calculation of the percentages, “don’t know,” “n/a,” or “no response” are treated as missing data and not included in the denominator.
## Data Sources

### Medicaid and Medicare Claims Data

**Purpose:** To develop health care outcome, prevention and performance measures for people served by the HCBS waiver programs. Measures of interest include:

- Cervical cancer screening
- Breast cancer screening
- Diabetes screening
- Use of emergency rooms
- Avoidable hospital conditions

**Population:** Includes members who were on a waiver or in an institution for six months or more in the year and who were MaineCare eligible for 11 or more months. If a person was on both the waiver and in an institution, the person was “assigned” to the group where s/he was for six months or more.

**Method:** Medicare and Medicaid claims were linked at the individual level. This was done using Medicare data provided by CMS and Medicaid data from the Maine Department of Health and Human Services.

**Year:** State Fiscal Year 2000

### Medicaid-only Data

**Purpose:** To examine the use of medications by people served by the HCBS waivers.

Indicators include:

- Use of inappropriate medications
- Use of psychotropic medications
- Use of 9 or more medications

**Population:** People served by the HCBS waiver programs and people in nursing facilities (NF) and ICF/MR's

**Method:** Analysis of MaineCare (Medicaid) claims data

**Year:** 2003

### Administrative Data

#### Medicare Assessment Data

**Purpose:** To use data from the MeCare Assessment to describe the characteristics and demographics of older adults and adults with disabilities.

**Population:** Older adults and adults with disabilities.

**Method:** Analysis of MeCare data

**Year:** Fiscal Year 2004; other most recent available.

#### Enterprise Information System (EIS)

**Purpose:** To use data from the EIS system to describe and examine characteristics of people with MR/A and to assess other patterns and trends.

**Population:** Adults with MR/A

**Method:** Analysis of EIS data

**Year:** Most recent available.
### Demographics

#### Population Descriptions

<table>
<thead>
<tr>
<th>Older Adults and Adults with Disabilities</th>
<th>Physically Disabled: Consumer Directed</th>
<th>Adults with MR/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population:</strong> The Older Adults and Adults with Disabilities Waiver serves people age eighteen (18) and older who meet nursing facility level of care and choose to receive services in their home.</td>
<td><strong>Population:</strong> The Physically Disabled Waiver serves people age eighteen (18) and older with severe physical disabilities who meet nursing facility level of care, are their own guardian and have the ability and desire to self-direct the services they receive in their home.</td>
<td><strong>Population:</strong> This waiver serves people with mental retardation and/or autism and who have an IQ of 70 or below.</td>
</tr>
<tr>
<td><strong>Eligibility:</strong> People must be determined eligible for NF level of care:</td>
<td><strong>Eligibility:</strong> People must be determined eligible for NF level of care:</td>
<td><strong>Eligibility:</strong> People who are currently on the waiver must have been certified as to medical necessity by a physician. People are reclassified annually. People must meet the ICF-MR level of care requirements.</td>
</tr>
<tr>
<td>• assistance and physical support in three of the following ADLs:</td>
<td>• assistance and physical support in three of the following ADLs:</td>
<td><strong>Services:</strong> Covered services include:</td>
</tr>
<tr>
<td>- bed mobility, transfer, locomotion, eating and toileting, OR</td>
<td>- bed mobility, transfer, locomotion, eating and toileting, OR</td>
<td>• habilitation services (e.g. residential training and day habilitation services)</td>
</tr>
<tr>
<td>• combination of three needs from:</td>
<td>• combination of three needs from:</td>
<td>• consultation services (including but not limited to licensed psychologists, speech pathologists, therapists and non-traditional communication assessments)</td>
</tr>
<tr>
<td>skilled nursing, cognition, behavior, and at least limited assist in 1 ADL from the following ADLs: bed mobility, transfer, locomotion, eating and toileting, OR</td>
<td>skilled nursing, cognition, behavior, and at least limited assist in 1 ADL from the following ADLs: bed mobility, transfer, locomotion, eating and toileting, OR</td>
<td>• respite services</td>
</tr>
<tr>
<td>• daily RN care, intensive therapies, other extensive assistance, as specified in rule</td>
<td>• daily RN care, intensive therapies, other extensive assistance, as specified in rule</td>
<td>• transportation services</td>
</tr>
<tr>
<td><strong>Services:</strong> Services include:</td>
<td><strong>Services:</strong> Services include:</td>
<td>• adaptive aids</td>
</tr>
<tr>
<td>• personal care</td>
<td>• personal care services</td>
<td>• communication services</td>
</tr>
<tr>
<td>• adult day health</td>
<td>• personal emergency response systems</td>
<td>• crisis intervention services</td>
</tr>
<tr>
<td>• transportation</td>
<td>• skills training</td>
<td>• environmental modification services</td>
</tr>
<tr>
<td>• homemaker</td>
<td>• case management</td>
<td>• personal support services</td>
</tr>
<tr>
<td>• personal emergency response systems</td>
<td></td>
<td>• supported employment services</td>
</tr>
<tr>
<td>• home health services</td>
<td></td>
<td>• maintenance therapy (i.e. occupational, speech therapy)</td>
</tr>
<tr>
<td>• respite care</td>
<td></td>
<td>Care management is a MaineCare state plan service provided by a combination of state workers and independent contractors.</td>
</tr>
<tr>
<td>• environmental modifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• care management/coordination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• independent living assessment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Demographics

Data Source: MeCare Data FY 2004
Medicaid/Medicare Claims 2000*

Top 10 Diagnoses

Older Adults (age 60+) (n=715)
- Hypertension: 60%
- Arthritis: 57%
- Depression: 43%
- Allergies: 41%
- Diabetes: 35%
- Cerebrovascular Accident: 34%
- Other Cardiovascular: 29%
- Congestive Heart Failure: 27%
- Hemiplegia/Hemiparesis: 24%
- Osteoporosis: 23%

Adults w/Disabilities (n=351)
- Depression: 40%
- Allergies: 40%
- Hypertension: 32%
- Arthritis: 26%
- Seizure Disorder: 23%
- Multiple Sclerosis: 18%
- Anxiety Disorder: 18%
- Diabetes: 18%
- Mental Retardation: 16%
- Other Cardiovascular: 15%

Age distribution

- 18-30: 6%
- 31-45: 11%
- 46-59: 17%
- 60-64: 7%
- 65-74: 16%
- 75-84: 25%
- 85+: 19%

Eligibility for Medicaid/Medicare*

Older Adults
- Dually Eligible for Medicaid/Medicare: 95%
- MaineCare/Medicaid only: 5%

Adults with Disabilities
- Dually Eligible for Medicaid/Medicare: 59%
- MaineCare/Medicaid only: 41%

Assistance with ADLs

Toilet Use
- Independent: 6%
- Needs Assistance: 75%
- Totally Dependent: 19%

Transfer
- Independent: 4%
- Needs Assistance: 80%
- Totally Dependent: 15%

Locomotion
- Independent: 11%
- Needs Assistance: 70%
- Totally Dependent: 15%

Bed Mobility
- Independent: 18%
- Needs Assistance: 71%
- Totally Dependent: 10%

Eating
- Independent: 63%
- Needs Assistance: 28%
- Totally Dependent: 9%

*Includes Older Adults and adults with Disabilities Waiver participants with 11 or more months of MaineCare and 6 months or more on the waiver.
Demographics

**Data Source:** MeCare Data FY 2001
Medicaid Claims 2000*
Medicaid/Medicare Claims 2000**

**Top 10 Diagnoses**

**People Under 60** (n=194)
- Quadriplegia ........................................ 25%
- Multiple Sclerosis .................................. 15%
- Arthritis .................................................. 15%
- Allergies ................................................... 13%
- Diabetes Mellitus .................................... 13%
- Cerebral Palsy ........................................ 13%
- Asthma ...................................................... 9%
- Depression .............................................. 7%
- Seizure Disorder ....................................... 7%
- Hypertension .......................................... 6%

**People Over 60** (n=53)
- Arthritis .................................................. 30%
- Osteoporosis ............................................ 21%
- Diabetes Mellitus ..................................... 19%
- Emphysema/COPD ..................................... 19%
- Cerebrovascular Accident .......................... 19%
- Quadriplegia ........................................... 15%
- Hypertension .......................................... 15%
- Multiple Sclerosis .................................... 11%
- Allergies ................................................... 9%
- Cancer ..................................................... 9%

**Age distribution**
- 0-18 .......... 1%
- 19-50 ....... 59%
- 51-60 ......... 19%
- 61-64 .......... 6%
- 65+ .......... 15%

*Includes Physically Disabled Waiver participants with 11 or more months of MaineCare and 6 months or more on the waiver.
Demographics

Data Source: Medicaid Claims 2000*
Medicaid/Medicare Claims 2000**

■ Age distribution
0-18 ...............4%
19-50 ............71%
51-60 ...........15%
61-64 ............3%
65+ ...............7%

■ Eligibility for Medicaid/Medicare**
Dually Eligible for Medicaid/Medicare
MaineCare/Medicaid only

62% 38%

*Includes MR Waiver participants with 11 or more months of MaineCare and 6 months or more on the waiver.
Quality management encompasses three functions:

- **Discovery**: Collecting data and direct participant experiences in order to assess the ongoing implementation of the program, identifying strengths and opportunities for improvement.
- **Remediation**: Taking action to remedy specific problems or concerns that arise.
- **Continuous Improvement**: Utilizing data and quality information to engage in actions that lead to continuous improvement in the HCBS program.

Background

In 2003, The Centers for Medicaid & Medicare Services (CMS) released the HCBS Quality Framework which outlines major areas of focus in the design of a HCBS Program and the quality management functions that are used to assess program goals.

Program design sets the stage for achieving desired outcomes. Program design addresses such topics as service standards, provider qualifications, assessment, service planning, monitoring participant health and welfare, and critical safeguards (e.g., incident reporting and management systems).

*Health Care Utilization was added as an additional area of focus in Maine.*
The Home and Community-Based Services (HCBS) Quality Framework provides a common frame of reference in support of productive dialogue among all parties who have a stake in the quality of community services and supports for older persons and individuals with disabilities. The Framework focuses attention on participant-centered desired outcomes along eight dimensions.

<table>
<thead>
<tr>
<th>Focus</th>
<th>Desired Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Access</td>
<td>Individuals have access to home and community-based services and supports in their communities.</td>
</tr>
<tr>
<td>Participant-Centered Service Planning and Delivery</td>
<td>Services and supports are planned and effectively implemented in accordance with each participant’s unique needs, expressed preferences and decisions concerning his/her life in the community.</td>
</tr>
<tr>
<td>Provider Capacity and Capabilities</td>
<td>There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants.</td>
</tr>
<tr>
<td>Participant Safeguards</td>
<td>Participants are safe and secure in their homes and communities, taking into account their informed and expressed choices.</td>
</tr>
<tr>
<td>Participant Rights and Responsibilities</td>
<td>Participants receive support to exercise their rights and accept personal responsibilities.</td>
</tr>
<tr>
<td>Participant Outcomes and Satisfaction</td>
<td>Participants are satisfied with their services and achieve desired outcomes.</td>
</tr>
<tr>
<td>System Performance</td>
<td>The system supports participants efficiently and effectively and constantly strives to improve quality.</td>
</tr>
<tr>
<td>Health Care Utilization</td>
<td>Participants are provided appropriate health care services.*</td>
</tr>
</tbody>
</table>

*Added for Maine
Participant Access

Desired Outcome: Individuals have access to home and community-based services and supports in their communities.

Program Design

**Older Adults and Adults with Disabilities**

**Assessment:** All people seeking nursing facility or adult waiver services have a face-to-face medical eligibility determination (MED) assessment. The assessment is intended to:
- provide timely and objective functional eligibility decisions for nursing home and state/Medicaid funded home care programs;
- educate consumers and families about in-home and community support services, residential, or institutional options; and
- support fair allocation of resources based on need.

**Who Conducts Assessment:** The Department of Health & Human Services contracts with one agency (currently Goold Health Systems), to operate the assessment program statewide. Assessors determine medical eligibility for over 14 different Medicaid and state funded in-home programs, including the two adult waivers, and nursing facility care.
- In order to avoid conflict of interest, the assessing services agency may not be a provider of long term care services.
- The Department has developed an automated system (MECARE) to collect and track the MED assessment data.

**Physically Disabled: Consumer Directed**

**Assessment:** All people seeking nursing facility or adult waiver services have a face-to-face medical eligibility determination (MED) assessment. The assessment is intended to:
- provide timely and objective functional eligibility decisions for nursing home and state/Medicaid funded home care programs;
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- In order to avoid conflict of interest, the assessing services agency may not be a provider of long term care services.
- The Department has developed an automated system (MECARE) to collect and track the MED assessment data.

**Adults with MR/A**

**Assessment:** All people seeking MR services have an assessment. The purpose of the assessment is:
- to assess eligibility for MR and MaineCare services;
- to determine if a person would otherwise qualify to live in an ICF-MR; and
- to determine the nature and timing of medically necessary services in a person’s Individual Plan.

**Who Conducts Assessment:** Regional office staff conduct initial assessments and reassessments for people seeking MR services. The assessment includes the development of an initial plan of care. Plans are generally reviewed annually or when there is a significant change.
Participant Access

Data Source: Assessment Survey 2003  
n=662

- “The assessment was very thorough and very informative. The nurse was very professional, willing to help in any way, willing to listen attentively and very concerned about helping us out in our situation—also a very nice person—personally very unbiased.”

- “The nurse was very helpful and pleasant. We had all our questions answered in detail. I would like to thank you guys for all the help I got from the information she gave me.”

- “Very courteous, helpful, nice. Explained anything difficult to understand. I was and am very appreciative of the services and thankful for a friendly face and friend.”

- “The nurse that came to my home was very nice to talk to and answered every question I need to know and explained it to me with no problems that I could not understand. She was very nice and polite to me and my family and was on time. Thank you very much.”

- “I don’t feel my assessment was fair. I need many more hours to be able to live on my own. Seems they would like it better if I went into a facility.”

- “Goold is always very good, however, we remain without services and it is very difficult and unsafe.”

Older Adults and Adults with Disabilities (waiver and non-waiver)

| Service options explained in assessment process | 85% |
| Asked what services wanted during assessment process | 77% |
| Nurse who did the assessment did not have trouble understanding their situation | 86% |
| Phone number given if they had questions | 81% |
| Opinions ignored about the care they needed | 5% |
### Participant Access

**Data Source:** Participant Experience Survey 2004  
n=177

#### Physically Disabled: Consumer-Directed

- First learned of consumer-directed waiver from:

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha One Staff</td>
<td>27%</td>
</tr>
<tr>
<td>Friends/Family</td>
<td>19%</td>
</tr>
<tr>
<td>Medical Provider</td>
<td>16%</td>
</tr>
<tr>
<td>Unsure/Don’t Remember</td>
<td>10%</td>
</tr>
<tr>
<td>EIM/Goold/State Staff</td>
<td>8%</td>
</tr>
<tr>
<td>Home Health Provider</td>
<td>6%</td>
</tr>
<tr>
<td>Vocational Rehab</td>
<td>3%</td>
</tr>
<tr>
<td>Program Literature</td>
<td>2%</td>
</tr>
<tr>
<td>Advocacy Group/Disability Organization</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>25%</td>
</tr>
</tbody>
</table>
**Participant Access**

**Data Source:** Family Survey National Core Indicators 2003

---

“Our BDS worker is very helpful. Always tries to get answers to my questions.”

“I feel that supports are not available at the level that we need to help keep our son home with us. And that we are not fully informed of the services that are out there.”

“We were very unhappy to lose our ISC caseworker. We needed someone to talk to a few times a year to tell us of services available and be a go-between for us to help.”

---

**Adults with MR/A**

- **Receive information on services and supports available** (n=316)
  - Always or Usually: 28%
  - Sometimes: 35%
  - Seldom/Never: 37%

- **Easy to understand information** (n=254)
  - Always or Usually: 48%
  - Sometimes: 44%
  - Seldom/Never: 9%

- **Enough information to participate in planning services** (n=285)
  - Always or Usually: 41%
  - Sometimes: 33%
  - Seldom/Never: 26%
Participant-Centered Service Planning and Delivery

**Desired Outcome:** Services and supports are planned and effectively implemented in accordance with each participant’s unique needs, expressed preferences and decisions concerning his/her life in the community.

### Program Design

<table>
<thead>
<tr>
<th>Older Adults and Adults with Disabilities</th>
<th>Physically Disabled: Consumer Directed</th>
<th>Adults with MR/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual Plan:</strong> The assessing services agency works with the participant to develop a plan of care. This plan includes the waiver services to be provided, the number of hours for each covered service and the provider type to deliver each service. The plan of care takes into account each person’s living arrangements, informal supports and services provided by other public and private funding sources. <strong>Choice:</strong> At the end of the assessment, the consumer signs a letter indicating their choice for either nursing facility or community services. If the consumer chooses community services, the home care coordinating agency then begins the process of arranging and coordinating the services as authorized in the assessment’s plan of care. <strong>Case Management:</strong> The Home Care Coordinating Agency, Elder Independence of Maine (EIM) receives a monthly per person payment to:  - arrange services  - coordinate and monitor care;  - calculate consumer co-payments  - contract with service providers  - pay claims;  - audit providers;  - participate in quality improvement activities.</td>
<td><strong>Individual Plan:</strong> The assessing agency works with participants to develop a plan of care. This plan includes waiver services to be provided, the number of hours for each service, and the provider type to deliver each service. The plan takes into account each person’s living arrangements, informal supports, and services provided by other public/private funding sources. <strong>Choice:</strong> At the end of the assessment, the consumer signs a letter indicating their choice for either nursing facility or community services. If the consumer chooses community services, the Provider/Case Management agency will implement skills training to assist the consumer as they prepare to hire and direct their waiver services. <strong>Case Coordination:</strong> The Provider/Case Management Agency, Alpha One, receives a monthly per person payment for:  - coordinating and implementing services;  - skills training;  - ensuring authorized services are delivered;  - serving as a resource for members to identify service options and service providers;  - processing claims;  - overseeing and assuring compliance, and conducting required utilization review activities.</td>
<td><strong>Individual Plan:</strong> Person-centered planning is a process that is directed by the individual or their representative, respects and assures the individual’s choices, is adaptable and creative and is meaningful and user friendly. The plan includes the medically necessary services to be provided, the frequency of service provision and the type of providers who will furnish the services. <strong>Choice:</strong> If a person meets the ICF-MR level of care, the case manager informs the individual and guardian of service alternatives and offers the individual and the guardian the opportunity to choose one of those alternatives in a choice letter. <strong>Case Management:</strong> The case manager convenes the service planning team, develops the individual plan, monitors the services, and assures that the services meet the needs set forth in the member’s plan.</td>
</tr>
</tbody>
</table>
Participant-Centered Service Planning and Delivery

Data Source: Home Care Satisfaction Survey 2004
Older Adults n=266
Adults w/Disabilities n=151

- “She is kind and easy to talk to. She understands me and knows how to get me the services I need. I trust her completely.”

- “My Mom's care coordinator is always nice and always very helpful. If I have a question for her and she doesn’t know the answer, she will look it up and will call me back giving me the information that I am looking for.”

- “Care coordinator is very caring person. Interested in the services I receive and very helpful in making sure services are running smoothly.”

- “It is difficult to service the hours needed as there are not enough PCA's to go around.”

- “They are cutting down hours which isn’t fair to us.”

Older Adults and Adults with Disabilities (waiver participants)

- **Need increased hours of home care services**
  - Older Adults: 18%
  - Adults w/Disabilities: 23%

- **Knowledge of EIM Care Coordinator**
  - Older Adults: 91%
  - Adults w/Disabilities: 87%

- **Need more help from Care Coordinator than I get**
  - Older Adults: 9%
  - Adults w/Disabilities: 10%
## Participant-Centered Service Planning and Delivery

**Data Source:** Participant Experience Survey
Consumer Directed 2004
n=177

### Physically Disabled: Consumer Directed

<table>
<thead>
<tr>
<th>Service</th>
<th>Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participated as much as wanted to in developing plan of care</td>
<td>95%</td>
</tr>
<tr>
<td>Talk with Alpha One staff when needed</td>
<td>95%</td>
</tr>
<tr>
<td>Alpha One staff respond in 24 hours</td>
<td>94%</td>
</tr>
</tbody>
</table>

*• “People at Alpha One are very helpful and very thoughtful—they give you ideas and counsel.”*

*• “Alpha One has always helped me. I just call anytime I need help.”*

*• “Alpha One has been very good to me over the years. They are the only program that can help me. I’m afraid of the prospect of a nursing home.”*

*• “I look forward to seeing my Alpha One caseworker, talking with her. If I have any problem (very rare), I call and they take care of it immediately.”*
### Participant-Centered Service Planning and Delivery

**Data Source:** Consumer Survey National Core Indicators 2004

<table>
<thead>
<tr>
<th>Adults with MR/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service coordinator helps with needs</strong> (n=231)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th> </th>
<th>71%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>94%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>4%</td>
</tr>
<tr>
<td>No</td>
<td>2%</td>
</tr>
</tbody>
</table>

| **Service plan includes things that are important to family member** (n=204) |
|---|---|
| Always or usually | 68% |
| Sometimes | 26% |
| Seldom or never | 6% |

| **Services and supports meet family’s needs** (n=277) |
|---|---|
| Always or usually | 59% |
| Sometimes | 32% |
| Seldom or never | 9% |

---

**Data Source:** Family Survey National Core Indicators 2004

“My daughter and I are very pleased with the support we receive. The people we work with are responsible and responsive. Thank you.”

“Our daughter is much happier and has a better outlook. She has learned and improved in countless areas such as reading, math, money management, telling and understanding time. This is the best program that she has ever had. I wish we had started earlier.”

---
Provider Capacity and Capabilities

**Desired Outcome:** There are sufficient HCBS providers and they possess and demonstrate the capability to effectively serve participants.

---

**Program Design**

**Older Adults and Adults with Disabilities**

**Providers:** Services are delivered through a network of more than 200 home health agencies, adult day service providers, personal care agencies, and independent nurse contractors. The Home Care Coordinating Agency, Elder Independence of Maine, contracts with each provider and conducts provider audits related to staffing, training, delivery of service and billing.

**Qualifications:** Professional staff (RN, LPN, therapists) must be fully licensed as documented by written evidence from the appropriate governing body. All professional staff must provide services only to the extent permitted by licensure and approval to practice conditions.

Other nonprofessional staff (e.g., CNAs, PCAs, HHAs) must have appropriate education, training and experience, as verified by the Home Care Coordinating Agency.

This includes verification that an individual is listed on the applicable registry and/or meets training requirements and has no record of a conviction or substantiated complaint of abuse, neglect, or misappropriation of member’s funds.

---

**Physically Disabled: Consumer Directed**

**Providers:** Services are delivered by personal attendants hired by the consumer.

**Qualifications:** Personal attendants must be at least seventeen (17) years old and have the ability to assist with activities of daily living.

An attendant cannot be an individual who has a notation on the Maine Registry of Certified Nursing Assistants of (a) any criminal convictions, except for Class D and Class E convictions over ten (10) years old that did not involve as a victim of the act, a patient, client, or resident of a health care entity; or (b) any specific documented findings by the State Survey Agency of abuse, neglect or misappropriation of property of a resident, client or patient.

---

**Adults with MR/A**

**Providers:** Services are provided by a network of profit and non-profit providers including individual and group living arrangements, employment and day services.

**Qualifications:**
- Consultation services must be provided by appropriately licensed professionals
- Providers of direct personal support and habilitation services must be approved by DHHS and complete approved competency based training for direct services staff; or demonstrate competency in areas required by DHHS.
- Other providers must be approved by DHHS.
Provider Capacity and Capabilities

Data Source: Home Care Satisfaction Survey
2003
Older Adults n=266
Adults w/Disabilities n=151

- “Very efficient. Goes right to work and knows what needs to be done.”
- “She does exactly what needs to be done without my telling her.”
- “She always does what I want and need her to do.”
- “…shows great concern for my welfare i.e. safety/taking meds on time/always asks for my needs. Sees that right food supplies are on hand for when she’s not here.”
- “A very nice person who takes my problems as if they were her own.”

Older Adults and Adults with Disabilities (waiver participants)

- **Worker is knowledgeable**
  - Older Adults
  - Adults w/Disabilities
  - 89%
  - 91%

- **Worker does tasks correctly**
  - Older Adults
  - Adults w/Disabilities
  - 82%
  - 87%

- **Worker shows interest in person**
  - Older Adults
  - Adults w/Disabilities
  - 89%
  - 93%
Reasons for delay: low pay and compatibility
“There are no benefits,”
“They didn’t understand duties involved,” and
“Lack of pay influenced the number of people
who applied and the quality of the applicants.”

Most common reasons for unhappy performance
(n=50):
Unhappy with how work got done (58%);
Timeliness (44%);
PA reliability (42%);
PA attitude/personality (38%);
PA ability to do tasks (16%);
and theft by PA (8%).

Other responses included boundaries sometimes
ignored, bringing their personal life to work, and
time management.

For those reporting unmet need (n=29), most
common tasks unable to be done because no one
was there to assist:
Bathing (34%);
Using toilet (28%);
Personal hygiene (24%);
Dressing (24%);
Transferring (24%);
Eating (17%)
### Provider Capacity and Capabilities

#### Data Source: Consumer Survey National Core Indicators 2004

<table>
<thead>
<tr>
<th>Adults with MR/A</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staff is nice at job/day activity</strong> (n=224)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td><strong>Home staff is nice</strong> (n=236)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

#### Data Source: Family Survey National Core Indicators 2003

| “These people [case workers] are always available and are very nice and willing to help in anyway they can. We are very pleased with the services we receive.” |
| “I am very impressed with her new caseworker who is working very hard to involve my daughter in more activities.” |
| “My son is very mildly retarded. He has a good support system except trying to get a hold of his caseworker. He always calls me back though but he never tells me of what services are available.” |

| **Service/support coordinator helps you get what you need** (n=278) |
| Always or usually | 65% |
| Sometimes | 27% |
| Seldom or never | 8% |

| **Supports are available when needed** (n=275) |
| Always or usually | 54% |
| Sometimes | 35% |
| Seldom or never | 11% |
Participant Safeguards

Desired Outcome: Participants are safe and secure in their homes and communities, taking into account their informed and expressed choices.

Program Design

**Older Adults and Adults with Disabilities**

- **Personal Emergency Response System** is a covered service under the waivers. This is an electronic device designed to let participants summon help in an emergency. It provides an additional level of safety to participants residing in the community.

- **Adult Protective Services** - The Bureau of Elder and Adult Services provides or arranges for services to protect incapacitated and dependent adults (age 18 and over) who are unable to protect themselves from abuse, neglect or exploitation. Professionals and direct care workers serving participants on the waivers are considered mandatory reporters.

- **Plan of Care Flexibility for Emergency/Acute Episodes** - Plans of care may be adjusted, on a temporary basis, in the event of an emergency or acute episode.

**Physically Disabled: Consumer Directed**

- **Personal Emergency Response System** is a covered service under the waivers. This is an electronic device designed to let participants summon help in an emergency. It provides an additional level of safety to participants residing in the community.

- **Adult Protective Services** - The Bureau of Elder and Adult Services provides or arranges for services to protect incapacitated and dependent adults (age 18 and over) who are unable to protect themselves from abuse, neglect or exploitation. Professionals and direct care workers serving participants on the waivers are considered mandatory reporters.

- **Plan of Care Flexibility for Emergency/Acute Episodes** - Plans of care may be adjusted, on a temporary basis, in the event of an emergency or acute episode.

**Adults with MR/A**

- **Crisis Team** - Each BDS region has a crisis team to provide assistance to individuals, families, guardians and providers. The team can provide outreach, support, consultation, education and in-home services. Each of the regional crisis teams also operates a residential service for short-term stabilization. Crisis services are available 24 hours a day and are available through a toll-free hotline.

- **Adult Protective Services** - The Department has a legislative mandate to assure the health and welfare of Maine citizens with MR. There is a compliment of adult protective workers in the state whose responsibility is to investigate and seek resolution to potentially harmful situations.

- **Reportable Events** - All individuals, staff of agencies, subcontractors and volunteers who provide residential, day, employment or other services to adults with mental retardation or autism are required to report events that have or may have an adverse impact upon the safety, welfare, rights or dignity of adults with mental retardation or autism.
### Participant Safeguards

**Data Source:** Home Care Satisfaction Survey 2003  
Older Adults n=266  
Adults w/Disabilities n=1651

- “Undependable timing and showing up.”
- “The only problem is back up staff when workers can’t come.”
- “When the worker doesn’t show up in the a.m., the agency doesn’t have a replacement and doesn’t call to let me know until my family is gone for the day!”

#### Older Adults and Adults with Disabilities (waiver participants)

<table>
<thead>
<tr>
<th>Description</th>
<th>Older Adults</th>
<th>Adults w/Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worker did not show up 3+ times within last 30 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Adults</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Adults w/Disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worker did not show up 2-3 times within last 30 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Adults</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Adults w/Disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worker did not show up once within last 30 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Adults</td>
<td>12%</td>
<td>16%</td>
</tr>
<tr>
<td>Adults w/Disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worker always shows up within last 30 days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Adults</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>Adults w/Disabilities</td>
<td>65%</td>
<td></td>
</tr>
</tbody>
</table>
Participant Safeguards

Data Source: Participant Experience Survey 2004
n=177

“I have fallen from my chair and am unable to move myself from the chair at all. When my PA didn’t show up I was in distress.”

“At night time if no one is here I feel vulnerable.”

“If I don’t have anyone to put me to bed, I have to stay in the chair all night. I can have a diabetic reaction and there is not always someone here.”

Two-thirds of those who requested equipment or changes received what they needed. Equipment mentioned: ramp, scooter, Hoyer lift, walk/roll in shower, wheelchair, bathroom modification, widen doorways.

Reason for not getting equipment or making changes: cost (mentioned most often), Housing Authority does not allow it, waiting list.

Additional training requested:
• “How to cope in emergency situations, what to do when no one is around.”
• “Help on screening people, background checks, interviewing, telephone responses.”
• “Tips on how to handle workers – some people don’t know how to ask for what they need in a tactful way so they don’t ask…”

Physically Disabled: Consumer Directed

- Ever used back-up system
  - 65%
- Felt unsafe - worker not present
  - 31%
- Injured by PA
  - 11%
- Special equipment or changes in home needed
  - 68%
- Enough training on how to:
  - Train Workers
  - 88%
Participant Safeguards

MR Mortality Review:
Summary - September 12, 2005

Time Period: February 2003 through August 2005

Total Deaths Reported: 101

Client Descriptive Profile:

<table>
<thead>
<tr>
<th>Profile</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>53</td>
<td>52%</td>
</tr>
<tr>
<td>Female</td>
<td>48</td>
<td>48%</td>
</tr>
<tr>
<td>Age at Death</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 to 35 Years</td>
<td>9</td>
<td>9%</td>
</tr>
<tr>
<td>36 to 45 Years</td>
<td>14</td>
<td>14%</td>
</tr>
<tr>
<td>46 to 55 Years</td>
<td>15</td>
<td>15%</td>
</tr>
<tr>
<td>56 to 65 Years</td>
<td>24</td>
<td>24%</td>
</tr>
<tr>
<td>66 Years &amp; Older</td>
<td>39</td>
<td>39%</td>
</tr>
<tr>
<td>Average Age 60 Years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guardianship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>25</td>
<td>27%</td>
</tr>
<tr>
<td>Private</td>
<td>49</td>
<td>52%</td>
</tr>
<tr>
<td>Self</td>
<td>20</td>
<td>21%</td>
</tr>
<tr>
<td>Cause of Death</td>
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</tr>
<tr>
<td>Cancer</td>
<td>14</td>
<td>14%</td>
</tr>
<tr>
<td>Cardiac</td>
<td>24</td>
<td>24%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>22</td>
<td>22%</td>
</tr>
<tr>
<td>Asperation Related</td>
<td>11</td>
<td>11%</td>
</tr>
<tr>
<td>Accidental</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>Infection/Sepsis</td>
<td>7</td>
<td>7%</td>
</tr>
<tr>
<td>Neurological</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>Renal Failure</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>11%</td>
</tr>
</tbody>
</table>

Data Source: Consumer Survey National Core Indicators 2004

- **Afraid at home** (n=246)
  - Rarely: 79%
  - Sometimes: 18%
  - Most of the time: 2%

- **Afraid in neighborhood** (n=239)
  - Rarely: 82%
  - Sometimes: 12%
  - Most of the time: 6%

Data Source: Family Survey National Core Indicators 2004

- **Day/employment setting is a healthy and safe environment**
  (n=281)
  - Always or usually: 89%
  - Sometimes: 10%
  - Seldom or never: 1%

- **Access to needed special equipment or accommodations**
  (n=101)
  - Always or usually: 65%
  - Sometimes: 21%
  - Seldom or never: 14%

- **Services provided right away when asked for in emergency or crisis**
  (n=153)
  - Always or usually: 52%
  - Sometimes: 19%
  - Seldom or never: 29%
Participant Rights and Responsibilities

Desired Outcome: Participants receive support to exercise their rights and accept personal responsibilities.

Program Design

### Older Adults and Adults with Disabilities

**Appeals and Grievances:**
- Consumers, families and service providers who are dissatisfied with the assessment, or with their services, may appeal the Department’s decision.
- Goold or Elder Independence of Maine informs the consumer about appeal rights.
- The Department’s Administrative Hearings Unit hears appeals.

**Advocate Services:**
- Consumers who wish to appeal may receive assistance from the Long-term Care Ombudsman Program, Legal Services for the Elderly, or Pine Tree Legal.

### Physically Disabled: Consumer Directed

**Appeals and Grievances:**
- Consumers, families and service providers who are dissatisfied with the assessment, or with their services, may appeal the Department’s decision.
- Goold or Alpha One informs the consumer about appeal rights.
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**Advocate Services:**
- Consumers who wish to appeal may receive assistance from the Long-term Care Ombudsman Program, Legal Services for the Elderly, or Pine Tree Legal.

### Adults with MR/A

**Appeals and Grievances:**
- Consumers, families and service providers who are dissatisfied with decisions made by the Department may appeal these decisions. There are a number of steps in an appeal process. This can include an appeal to the case manager, the Mental Retardation Team Leader and/or a formal hearing with administrative hearings unit. People who appeal may receive assistance from the Office of Advocacy.

**Advocate Services:**
- The Office of Advocacy advocates for those served by the Department in all matters pertaining to rights and dignity. Advocates are the investigators of allegations of abuse, neglect, and exploitation pertaining to adults with mental retardation in Maine.
Participant Rights and Responsibilities

Data Source: Home Care Satisfaction Survey
2004
Older Adults n=266
Adults w/Disabilities n=151

“I would like help to do the things I can’t do that is not on the list. Like washing curtains and windows and put curtain up also ironing and doing my mail. As these are the things they are not allowed to do.”

“If only this agency would allow workers to take their clients to Dr.’s appointments. Travel would be easier.”

“The help is appreciated by my wife and me. We would like if there was less turnover in help and have some say in who is to come to our house.”

Data Source: Assessment Survey 2003
n=662

Older Adults and Adults with Disabilities (waiver participants)

- Want more say in who helps
  - Older Adults
    - Adults with Disabilities
    - 17%
    - 26%

- Want more choice in services
  - Older Adults
    - Adults with Disabilities
    - 17%
    - 21%

Older Adults and Adults with Disabilities (waiver and non-waiver)

- Informed that appeal could be filed if disagree w/assessment
  - 69%

- Service complaint process explained
  - 78%
Participant Rights and Responsibilities

| Data Source: | Participant Experience Survey 2004  
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=177</td>
</tr>
</tbody>
</table>

### Physically Disabled: Consumer Directed

- Worker respects privacy: 97%
- Received information on filing an appeal: 79%
- Knowledge of contact if have complaint: 63%
- Workers respect confidentiality: 91%

(Data Source: Participant Experience Survey 2004, n=177)
Participant Rights and Responsibilities

**Data Source:** Consumer Survey National Core Indicators 2004

**Adults with MR/A**

- **Be alone - satisfaction with amount of privacy (n=235)**
  - Yes: 90%

- **Choose agencies or providers (n=257)**
  - Always or usually: 49%
  - Sometimes: 28%
  - Seldom or never: 23%

- **Choose support workers (n=248)**
  - Always or usually: 33%
  - Sometimes: 24%
  - Seldom or never: 43%

- **Have control and/or input on hiring and management of support workers (n=190)**
  - Always or usually: 27%
  - Sometimes: 19%
  - Seldom or never: 54%

- **Want to have control and/or input on hiring and management of support workers (n=185)**
  - Always or usually: 47%
  - Sometimes: 32%
  - Seldom or never: 21%

---

“Data Source: Family Survey National Core Indicators 2004

“There needs to be more respite opportunities specific to individual needs and personal safety. I have to find respite providers myself and use family support funds to fill in gaps of care.”

“It would be nice to get paid for taking care of my brother. Other people do because they are not related. I don’t know why they pay one person and not a relative. If the relative didn’t want the person then they would have to put him with someone else.”
### Participant Outcomes and Satisfaction

**Desired Outcome:** Participants are satisfied with their services and achieve desired outcomes.

## Program Design

### Older Adults and Adults with Disabilities

**Participant Outcomes**
Outcomes are monitored using a combination of administrative and other data.
- The MeCare long term care assessment system includes demographic, cognitive, behavioral and other assessment information for older adults and adults with disabilities. This data is available to examine individual cases and system level trends and reports on a regular and as needed basis.
- Claims data are available to examine health careutilizations.

**Participant Satisfaction**
- Consumers are surveyed every year to determine their satisfaction with services, satisfaction with case management services and the process used to assess their needs. These include both mail and in-person surveys.

### Physically Disabled: Consumer Directed

**Participant Outcomes**
Outcomes are monitored using a combination of administrative and other data.
- Long term care assessment data for people who self-direct services is in the process of being entered into the MeCare automated LTC system. This will allow program managers to examine individual cases and trends on a regular and as needed basis.
- Claims data are available to examine the health care utilization of people who self-direct services.

**Participant Satisfaction**
Consumers were surveyed in 2004 to determine their satisfaction and experience directing their own services including satisfaction with training, hiring, and managing workers.

### Adults with MR/A

**Participant Outcomes**
Outcomes are monitored using a combination of administrative and other data.
- The DHHS Enterprise Information System provides up-to-date and comprehensive information on incidents, restraint use, reportable events and case management notes.
- Claims data are available to examine health care utilization.

**Participant Satisfaction**
Consumers, family members and guardians are surveyed every year. One third of all consumers and/or family members and guardians are asked to complete a satisfaction survey each year.
## Participant Outcomes and Satisfaction

**Data Source:** Home Care Satisfaction Survey 2004  
Older Adults n=266  
Adults w/Disabilities n=151

### Older Adults and Adults with Disabilities (waiver participants)

<table>
<thead>
<tr>
<th></th>
<th>Older Adults</th>
<th>Adults with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Would recommend worker</strong></td>
<td>88%</td>
<td>87%</td>
</tr>
<tr>
<td><strong>Go places when needed</strong></td>
<td>65%</td>
<td>65%</td>
</tr>
</tbody>
</table>

### Rating of Health

<table>
<thead>
<tr>
<th>Health Rating</th>
<th>Older Adults</th>
<th>Adults with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Excellent</strong></td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Very Good</strong></td>
<td>6%</td>
<td>11%</td>
</tr>
<tr>
<td><strong>Good</strong></td>
<td>24%</td>
<td>28%</td>
</tr>
<tr>
<td><strong>Fair</strong></td>
<td>40%</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Poor</strong></td>
<td>25%</td>
<td>20%</td>
</tr>
</tbody>
</table>
## Participant Outcomes and Satisfaction

**Data Source:** Participant Experience Survey  
2004  
n=177

### Physically Disabled: Consumer Directed

<table>
<thead>
<tr>
<th>Item</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would recommend worker</td>
<td>94%</td>
</tr>
<tr>
<td>Would recommend services/supports</td>
<td>98%</td>
</tr>
<tr>
<td>Ability to go to doctor or grocery store when needed</td>
<td>89%</td>
</tr>
<tr>
<td>Want to do outside activities not currently doing</td>
<td>46%</td>
</tr>
</tbody>
</table>

### Rating of Health

<table>
<thead>
<tr>
<th>Rating</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>12%</td>
</tr>
<tr>
<td>Very Good</td>
<td>23%</td>
</tr>
<tr>
<td>Good</td>
<td>24%</td>
</tr>
<tr>
<td>Fair</td>
<td>27%</td>
</tr>
<tr>
<td>Poor</td>
<td>14%</td>
</tr>
</tbody>
</table>
## Participant Outcomes and Satisfaction

### Data Source: Consumer Survey National Core Indicators 2004

- 83% say they can see their friends when they want to see them. (n=234)
- 90% report they have a best friend or someone they are really close to. (n=225)
- 77% report they have friends they like to talk to or do things with that are not staff or family. (n=255)

### Health Care

- 94% Had physical exam in last year
- 46% Women had gyn exam in past year
- 58% Had routine dental exam in last 6 months

### Adults with MR/A

<table>
<thead>
<tr>
<th>Activity</th>
<th>Yes</th>
<th>Sometimes</th>
<th>Seldom or never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go shopping (n=426)</td>
<td>95%</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Go on errands/appointments (n=426)</td>
<td>99%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Go out for entertainment (n=423)</td>
<td>90%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Eat at home (n=425)</td>
<td>94%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Go to religious services (n=345)</td>
<td>55%</td>
<td>2%</td>
<td>43%</td>
</tr>
<tr>
<td>Go to clubs/community meetings (n=408)</td>
<td>34%</td>
<td>2%</td>
<td>64%</td>
</tr>
<tr>
<td>Have transportation (n=408)</td>
<td>85%</td>
<td>15%</td>
<td>0%</td>
</tr>
</tbody>
</table>

### Data Source: Family Survey National Core Indicators 2004

- Satisfied with services and support (n=301)
  - Always or usually: 62%
  - Sometimes: 33%
  - Seldom or never: 5%
System Performance

Desired Outcome: The system supports participants efficiently and effectively and constantly strives to improve quality.

Program Design: A number of methods are used to assess, review, evaluate and analyze the performance of the HCBS programs for older adults and adults with disabilities.

Older Adults and Adults with Disabilities

Discovery Methods
Surveys: Consumer surveys
Case Management Activities: contacts with individuals
In-home Visits: Visits to a sample of waiver participants by state QA/QI staff.
Record Reviews: Review of plans of care and services delivered.

Reports from the McCare LTC System:
Common condition/diagnosis, ADL and IADL needs, advance directives, case mix of participants, cognitive and behavioral conditions, community support available, living arrangements, level of care

Review of other operations data:
Complaint/call log, hearings and appeals, APS data, claims data, waiting list reviews, case conferences

Contract Reviews: Contract compliance
Financial Record Reviews: Review of billings and time sheets.

Key Informant Meetings: Monthly systems meeting (DHHS, EIM and GHS, Alpha One), meetings with stakeholder groups.

Quality Improvement/Quality Assurance:
Quality improvement opportunities are identified on an ongoing basis. Examples of quality improvement projects include: falls prevention and reduction pilot project; use of pharmacy consultant for medication review; collaborative project with the Bureau of Medical Services and the Bureau of Health to address the needs of people with diabetes.

Physically Disabled: Consumer Directed

Discovery Methods
Surveys: Consumer surveys
Case Management Activities: Contacts with individuals
In-home Visits: Visits to a sample of waiver participants by state QA/QI staff
Record Reviews: Desk reviews of records

Review of other operations data:
Complaint/call log, hearings and appeals, APS data, claims data, waiting list reviews, case conferences

Contract Reviews: Contract compliance
Financial Record Reviews: Review of billings and time sheets.

Key Informant Meetings: Monthly systems meeting (DHHS, EIM and GHS, Alpha One), meetings with stakeholder groups.

Adults with MR/A

Discovery Methods
Surveys: Consumer, family guardian surveys and provider surveys
Case Management Activities: Contacts with individuals
Record Reviews: Review of plans of care
Management Reports from the EIS System including:
• reportable events • restraint use • deaths
• case management notes
• resolution of complaints and issues
• adult protective services
• preventive health services

Review of other operations data:
• hearings and appeals • claims data • waiting lists

Contract Reviews
Financial Record Reviews

Key Informant Meetings:
MR Management team meetings
Regional (lead) Team meetings with providers
Meetings with stakeholder groups
Mortality review meetings

Quality Improvement/Quality Assurance:
The QI/QA System for Adult MR Services provides ongoing review of activities, ensuring health and safety, reviewing individual unmet needs, measuring people’s involvement in their communities and monitoring the many requirements which govern the Department’s delivery of services.

Collaborative Quality Improvement Project: The MR Program and the Elderly and Disabled Program (BEAS) are working on a collaborative project to leverage the Enterprise Information System to include incident/issue reporting and management function for Older Adults and Adults with Physical Disabilities, including those who self-direct services.

Maine Elder Death Analysis Review Team (MRAD): The MRAD was formed in 2003 under the auspices of the Attorney General, and is charged with examining deaths and cases of serious bodily injury associated with suspected abuse or neglect of elderly and vulnerable adults. The team includes representatives from law enforcement, prosecutors, victim advocates, licensing and certification, adult protective services and mental health meets monthly to review selected cases and to identify whether systems whose responsibility is to protect victims were sufficient or need improvement. MEDART seeks to foster system change that will improve the response to victims and prevent similar outcomes in the future.
System Performance

Data Source: Administrative Claims FY 2004

Waiver Cost Per Person

- Older Adults and Adults with Disabilities Waiver: $12,799
- Physically Disabled Waiver Consumer Directed: $28,107

Population Size

- Physically Disabled Waiver* Consumer Directed: n=325
- Older Adults and Adults with Disabilities Waiver**: n=1,371
- Nursing Facility: n=8,378

Costs (waiver and all other)

- Physically Disabled Waiver Consumer Directed: $12,533,923
- Older Adults and Adults with Disabilities Waiver: $27,067,262
- Nursing Facility: $270,092,851

* Services for physically disabled-consumer directed waiver participants includes personal care services, emergency response and skills training.

** Services for older adults and adults with disabilities include personal care, day health, transportation, homemaker, emergency response, home health, respite, environmental modifications, case management, independent living assessment.
**System Performance**

**Data Source:** Administrative Claims FY 2004

**Waiver Cost Per Person**

- ICF MR
  - $33,955,975

- Adults with MR/A Waiver
  - $228,029,246

**Population Size**

- ICF MR
  - n=236
  - 9% of total

- Adults with MR/A Waiver
  - n=2,489
  - 91% of total

**Costs (waiver and all other)**

- ICF MR
  - $33,955,975
  - 13% of total

- Adults with MR/A Waiver
  - $228,029,246
  - 87% of total

* MR waiver services include habilitation services, consultation, respite, transportation, adaptive aids, communication services, crisis intervention, environmental modification, personal support, supported employment and maintenance therapy.
Health Care Utilization

**Desired Outcome:** Participants are provided appropriate health care services.

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**Program Design**

- **Older Adults and Adults with Disabilities**
- **Physically Disabled: Consumer Directed**
- **Adults with MR/A**

---

**MaineCare Members**

In addition to services provided through the HCBS waivers, people on the MaineCare program are also eligible for a wide range of health care services including, but not limited to the following:

- Hospital Services (inpatient and outpatient)
- Physician Services
- Ambulatory Care Services
- Ambulance Services
- Medications
- Mental Health Services
- Laboratory Services
- Other
## Health Care Utilization / Hospital Use

### Data Source:
Medicaid and Medicare Claims 2000

### Most common diagnosis for ER visits (not resulting in an inpatient stay)
- **Older Adults**
  - Urinary Tract Infection
  - Constipation
  - Congestive Heart Failure
  - Chest Pain
- **Adults w/Disabilities**
  - Multiple Sclerosis
  - Other Convulsions
  - Urinary Tract Infection
  - Chest Pain
- **Physically Disabled - CD**
  - Urinary Tract Infection
  - Migraine
  - Lumbago
  - Bronchitis

### Percentage of people with at least 1 Emergency Room (ER) visit (not resulting in an inpatient stay)

<table>
<thead>
<tr>
<th>Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults, waiver (n=698)</td>
<td>50%</td>
</tr>
<tr>
<td>Adults with Disabilities, waiver (n=309)</td>
<td>44%</td>
</tr>
<tr>
<td>Physically Disabled, CD, waiver (n=286)</td>
<td>48%</td>
</tr>
<tr>
<td>NF Residents (n=5081)</td>
<td>27%</td>
</tr>
</tbody>
</table>

### For those people with at least one ER visit (not resulting in inpatient stay)

<table>
<thead>
<tr>
<th>Group</th>
<th>Average number of ER visits/year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults, waiver (n=348)</td>
<td>2.3</td>
</tr>
<tr>
<td>Adults with Disabilities, waiver (n=135)</td>
<td>2.9</td>
</tr>
<tr>
<td>Physically Disabled, CD, waiver (n=137)</td>
<td>3.0</td>
</tr>
<tr>
<td>NF Residents (n=1386)</td>
<td>1.8</td>
</tr>
</tbody>
</table>

Does not include ER visits that result in mental health inpatient or outpatient visits.
Older Adults and Adults with Disabilities

Potentially avoidable hospitalization conditions include:
- asthma
- pneumonia
- kidney and urinary tract infections
- severe nose and throat infections
- gastroenteritis
- congestive heart failure

Pneumonia, kidney and UTI infections, and congestive heart failure had the highest admission rates.

MaineCare managed care members reported an average rate of 0.60% admissions for these conditions.

### Avoidable Hospitalizations (AH)

<table>
<thead>
<tr>
<th>Group</th>
<th>Percent with AH in year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults (n=698)</td>
<td>16%</td>
</tr>
<tr>
<td>Adults with Disabilities (n=309)</td>
<td>8%</td>
</tr>
<tr>
<td>Physically Disabled, CD (n=286)</td>
<td>12%</td>
</tr>
<tr>
<td>NF Residents (n=5081)</td>
<td>9%</td>
</tr>
</tbody>
</table>
Health Care Utilization / Hospital Use

Data Source: Medicaid and Medicare Claims 2000

- **Most common diagnosis for ER visits (not resulting in inpatient stay)**
  - Persons with MR/A, waiver
    - Other Convulsions
    - Urinary Tract Infection
    - Chest Pain
  - ICF MR
    - Other Convulsions
    - Pneumonia

- **Percent of people with at least one Emergency Room (ER) visit (not resulting in inpatient stay)**
  - Adults with MR/A, waiver (n=1792)
    - ICF MR (n=273)
      - 35%
      - 32%

- **For those with at least one ER visit**
  - Adults with MR/A, waiver (n=622)
    - ICF MR (n=88)
      - 2.4
      - 1.7

- **Average number of ER visits/year (not resulting in inpatient stay)**
Health Care Utilization / Hospital Use

Data Source: Medicaid and Medicare Claims 2000

- Adults with MR/A, waiver, n=1,792
- ICF MR, n=273

Potentially avoidable hospitalization conditions include:
- asthma
- pneumonia
- kidney and urinary tract infections
- severe nose and throat infections
- gastroenteritis
- congestive heart failure

Pneumonia, kidney and UTI infections, and congestive heart failure had the highest admission rates.

MaineCare managed care members reported an average of 0.60 avoidable hospitalizations per 100 members in 2003.

### Avoidable Hospitalizations (AH)

<table>
<thead>
<tr>
<th>Adults with MR/A (n=1792)</th>
<th>Percent with AH in year</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICF MR (n=273)</td>
<td>1%</td>
</tr>
</tbody>
</table>

Adults with MR/A (waiver and non-waiver)
### Health Care Utilization / Prevention and Screening

#### Data Source: Medicare and Medicaid Claims 2000

This report uses performance indicators that are similar to the HEDIS measures.

Health Plan Employer Data and Information Set (HEDIS) is a standardized measurement set that uses consistent performance indicators which can be compared with other sectors of MaineCare as well as other states.

In Maine we used specified HEDIS algorithms to calculate our rates using claims data submitted by providers, dependent on the accuracy of provider’s coding.

#### Older Adults and Adults with Disabilities (waiver and non-waiver)

<table>
<thead>
<tr>
<th>Cervical Cancer Screening in last 2 years (ages 21-64)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults, Waiver ....................... n=33</td>
</tr>
<tr>
<td>Adults w/Disability, Waiver .......... n=171</td>
</tr>
<tr>
<td>Physically Disabled Waiver-CD .... n=136</td>
</tr>
<tr>
<td>NF Residents ............................. n=297</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breast Cancer Screening in last year (ages 52+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults, Waiver ....................... n=419</td>
</tr>
<tr>
<td>Adults w/Disability, Waiver .......... n=49</td>
</tr>
<tr>
<td>Physically Disabled Waiver-CD .... n=77</td>
</tr>
<tr>
<td>NF Residents ............................. n=3,088</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diabetes - Hemoglobin Test in last year (ages 18+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults, Waiver ....................... n=229</td>
</tr>
<tr>
<td>Adults w/Disability, Waiver .......... n=45</td>
</tr>
<tr>
<td>Physically Disabled Waiver-CD .... n=58</td>
</tr>
<tr>
<td>NF Residents ............................. n=1,201</td>
</tr>
</tbody>
</table>
Health Care Utilization / Prevention and Screening

**Data Source:** Medicare and Medicaid Claims 2000

This report uses similar performance indicators to the HEDIS measures.

Health Plan Employer Data and Information Set (HEDIS) is a standardized measurement set that uses consistent performance indicators which can be compared with other sectors of MaineCare as well as other states.

In Maine we used HEDIS algorithms to calculate rates using claims data submitted by providers. This calculation is dependent on the accuracy of provider's coding.

### Adults with MR/A (waiver and non-waiver)

<table>
<thead>
<tr>
<th>Screening Area</th>
<th>Group</th>
<th>Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cervical Cancer Screening in last 2 years (ages 21-64)</strong></td>
<td>Adults w/MR/A, Waiver ............. n=692</td>
<td>53%</td>
</tr>
<tr>
<td></td>
<td>ICF-MR Residents .................. n=103</td>
<td>37%</td>
</tr>
<tr>
<td><strong>Breast Cancer Screening in last year (ages 52+)</strong></td>
<td>Adults w/MR/A, Waiver ............. n=193</td>
<td>65%</td>
</tr>
<tr>
<td></td>
<td>ICF-MR Residents .................. n=41</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Diabetes HbA1c Test in last year (ages 18+)</strong></td>
<td>Adults w/MR/A, Waiver ............. n=99</td>
<td>79%</td>
</tr>
<tr>
<td></td>
<td>ICF-MR Residents .................. too small to report</td>
<td></td>
</tr>
</tbody>
</table>
The Beers’ medications list is a widely used consensus criteria for potentially inappropriate medication use in older adults. Some of the most common potentially inappropriate medications used in 2003 include:

- Amitriptyline (Elavil) - antidepressant
- Fluoxetine (Prozac) - antidepressant
- Nitrofurantoin (Macrobid) - antibiotic for UTI
- Promethazine (Phenergan) - antihistamine

Psychotropic medication classes include:
- antianxiety agents
- antidepressants
- antipsychotic hypnotics
- stimulants
- miscellaneous psychotherapeutics

The top three psychotropic medications used in 2003 were:
- Ativan (Lorazepam) - antianxiety
- Paroxetine (Paxil) - antidepressant
- Zoloft (Sertraline) - antidepressant
The Beers’ medications list is a widely used consensus criteria for potentially inappropriate medication use in older adults. Some of the most common potentially inappropriate medications used in 2003 include:

- (Mellaril) - antipsychotic
- Diazepam (Valium) - antianxiety
- Fluoxetine (Prozac) - antidepressant

Psychotropic medication classes include antianxiety agents, antidepressants, antipsychotic hypnotics, stimulants, miscellaneous psychotherapeutics.

The top two psychotropic medications used in 2003 were:

- Risperdal (Risperidone) - antipsychotic
- Zoloft (Sertraline) - antidepressant

**Data Source:** Medicaid Claims 2003

### Adults with MR/A

#### Use of potentially inappropriate medication for people age 65+

- Adults with MR/A, waiver ...................... n=168
- ICF MR ........................................... n=21
  - 38%

- ICF MR ........................................... n=21
  - 33%

#### Use of psychotropic medications

- Adults with MR/A, waiver ...................... n=2,267
- ICF MR ........................................... n=216
  - 63%

- ICF MR ........................................... n=216
  - 65%

#### Use of 9 or more medications

- Adults with MR/A, waiver ...................... n=2,267
- ICF MR ........................................... n=216
  - 11%

- ICF MR ........................................... n=216
  - 14%

#### Use of 15 or more medications

- Adults with MR/A, waiver ...................... n=2,267
- ICF MR ........................................... n=216
  - 1%

- ICF MR ........................................... n=216
  - 1%

#### Use of 5 or more prescribing physicians

- Adults with MR/A, waiver ...................... n=2,267
- ICF MR ........................................... n=216
  - 5%

- ICF MR ........................................... n=216
  - 4%

The Beers’ medications list is a widely used consensus criteria for potentially inappropriate medication use in older adults. Some of the most common potentially inappropriate medications used in 2003 include:

- (Mellaril) - antipsychotic
- Diazepam (Valium) - antianxiety
- Fluoxetine (Prozac) - antidepressant

Psychotropic medication classes include antianxiety agents, antidepressants, antipsychotic hypnotics, stimulants, miscellaneous psychotherapeutics.

The top two psychotropic medications used in 2003 were:

- Risperdal (Risperidone) - antipsychotic
- Zoloft (Sertraline) - antidepressant

**Data Source:** Medicaid Claims 2003