A Cross-System Profile of Maine's Long Term Support System

A New View of Maine's Long Term Services and Supports and the People Served

March 2009

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This document was prepared by the Muskie School of Public Service at the University of Southern Maine for the Maine Department of Health and Human Services.

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Introduction

Introduction

This document provides a new way of looking at Maine's long term services and supports, with an emphasis on developing a common approach for describing and analyzing long term services and supports across programs. Creating this cross-system view required creating some new vocabulary and new strategies for defining population groups. This section describes the key features of this new approach, the value of a comparative view, as well as some cautions about drawing quick conclusions based on those comparisons.

A New Vocabulary

For a variety of very legitimate reasons, different program areas tend to use their own vocabulary to describe the services they offer. While this vocabulary is important within a program area, it often can limit communication and comparisons across programs. This document introduces a new vocabulary for grouping and describing services across population groups. While this terminology may seem foreign at first, it is intended to foster an easier translation across population groups. See PROCESS AND APPROACH for more information.

New Strategies for Identifying People with a Continuing Need for Services

Not everyone accessing long term services and supports has a continuing need for those services. For example, most people experiencing mental illness do not have a long term need for support. Some people accessing nursing facility services are there only temporarily before returning home. DHHS developed new strategies for distinguishing people with a continuing need for services and supports from those with only a short term need for services. This report represents the first application of these data definitions and for some population groups the results look different from previous population estimates. DHHS plans to get a better understanding of those differences in the second phase of this project, and will further refine its population definitions. See PROCESS AND APPROACH for more information.

Orientation Around Populations, Not Programs

A conscious effort was made to organize this profile around the populations served rather than the programs serving them. For that reason, the profile captures information on all of the services accessed by each population group, not only those services administered by a particular program. This broader view provides important information about the full range of service utilization for each population group.

Uses for a Cross-Systems View of Long Term Services and Supports

There are many ways Maine can use this cross-systems view. DHHS can use this profile:

Baseline Assessment and Goal Setting. As a baseline assessment of Maine's long term support system, supporting decision making around long term, system wide goals for redistributing services across settings.

Information Sharing. As a mechanism for fostering greater understanding across programs, facilitating greater collaboration and coordination. Different programs may find opportunities to draw on the expertise of another program to improve their own.

Identifying Policy Questions. To identify common or emerging policy questions that should be addressed. For example, what are the implications of an aging population on all Maine's long term support systems? Are there common needs across population groups that can be addressed with common solutions?

Looking at Cost-Drivers. As a basis for looking at the differences in cost-drivers across population groups. Why are there differences? Is there anything that can be learned about one program that can benefit another?

Making Comparisons *versus* Drawing Conclusions

While there is considerable value in being able to compare across programs, there is considerable danger in drawing quick conclusions from those comparisons. Different population groups have different needs (*e.g.*, some people have an intermittent need for physical assistance while persons with a cognitive disability might need ongoing assistance with decision making). Different programs also have different constraints on how they meet those needs (*e.g.*, budgetary or legal limits on discretion). The similarities and differences between programs serve only as a basis for further examination: What factors are underlying these differences? Are these legitimate differences? Or are they the result of policy or operational decisions that need correction? These questions need to be answered before one can responsibly draw conclusions that have budgetary or policy implications for programs and services.

Process & Approach

Process & Approach

The State Profile Tool grant is a three-year grant from the Centers for Medicare and Medicaid Services (CMS) to the Maine Department of Health and Human Services (DHHS). This State Profile completes the first phase of the work, which involved profiling the long term services and supports provided to each of these population groups:

- Adults with mental illness
- Older adults and adults with disabilities
- Adults with brain injury
- Adults with developmental disabilities
- Children with need for continuing services and supports

The profile follows the State Profile Tool Technical Assistance Guide[1] provided by CMS and includes information on:

- System administration and management information
- Information describing each program
- Demographic and utilization data
- Key system components associated with a balanced long term supports system

Under the SPT grant, DHHS has partnered with the Muskie School of Public Service to collect and analyze the information in the profile. This information can be used by DHHS to establish a baseline and serve as a foundation for setting goals for its long term services and supports. In addition, through this project a number of tools were produced that may be of ongoing use to DHHS, including:

- Standard definitions for the populations served and services provided that can be used to foster greater consistency in data analysis and reporting.
- A common framework and vocabulary for describing services and systems and presenting data across programs and population groups, promoting a cross-systems view of DHHS services.
- A preliminary listing of characteristics designed to measure the restrictiveness of a setting. With refinement, this tool may have the potential to guide policy and purchasing decisions. It might also be used as a standardized tool for assessing whether a setting is more like an institution or a home.
- Criteria for evaluating key system components that can be used as a benchmark for systems improvements.

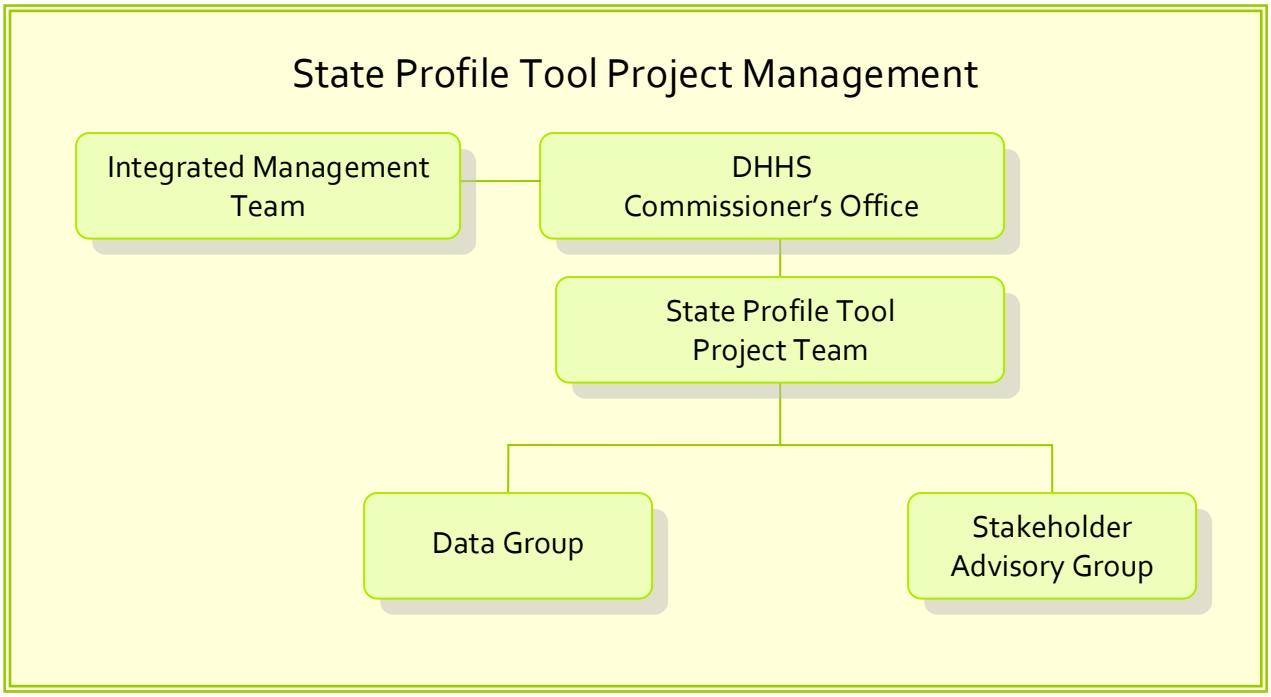
In the second phase of the grant, the remaining 18 months, Maine will work with CMS' "National Balancing Indicator Consultant," who will be using the information gathered in the state profiles to inform the development of national balancing indicators.

Project Organization

This project is directed by the Commissioner's Office and involves the participation of staff from across DHHS. A project team is chaired by staff from the Commissioner's Office and comprises policy-level staff. This team oversees the development of the state profile and all other project activities. The data group is chaired by

[1] Eiken, Steven. 2006. Technical Assistance Guide to Assessing a State's Long term Care System. Thomson Medstat.

DHHS' director of quality improvement and focuses on developing data specifications, consistent standards for pulling and interpreting data, and will work with the National Balancing Indicator Consultant to complete the second phase of the project. A stakeholder advisory group has provided feedback and guidance on the project team's strategies for completing the state profile. In the second phase of the project the stakeholder group will be asked to help DHHS determine the best strategies for translating the information gathered in the State Profile into goals and policy decisions going forward. The Commissioner's Office links the State Profile Tool back to DHHS' Integrated Management Team. Staff from the Muskie School participated on the project team, the data group and the stakeholder advisory group.



The State Profile Tool Requirements

The State Profile Tool Technical Assistance Guide outlines the information to be included in the profile. Items to be included are:

System Administration and Management Information

The basic structure of state and local administration of home and community-based programs, including the state agencies responsible for long term support programs, and the population groups they serve, the agencies that administer these programs at the local level; recent organizational changes and their rationale; systems change initiatives in progress; the legislature's role in systems change; and an overview of the role of consumers and advocates in systems change

Information for Each Program

A brief description of each home and community-based program for the population group including eligibility criteria; funding sources; maximum benefit amount, if any; whether there is a waiting list and how many individuals are currently waiting; and commonly used services.

Demographic and Utilization Data

For each population group, data that indicates the demand for long term support services and the relative use of institutional and community long term supports, including current, historical and projected trends;

relative spending for institutional and community long term support services; current and historical institutional care utilization; and current and historical home and community-based utilization.

Key System Components

The state's experience with eight system components associated with rebalanced long term support systems: consolidated state agencies; single access points; institution supply controls; transition from institutions; a continuum of residential options; home and community-based services infrastructure development; consumer direction; quality management.

Developing a Cross-Systems Vocabulary for Services

For a variety of very legitimate reasons, different program areas use their own vocabulary to describe the services they offer. While this vocabulary is important within a program area, it often can limit communication across programs. Below is a first cut at an alternative vocabulary for grouping and describing services across population groups. While this terminology may seem foreign at first, it is intended to foster an easier translation across population groups. The first four categories of services are provided in the community, not as part of a residential or institutional service.

Service Coordination

Typically, this category of services includes case management services, provided to a particular population group. However, some people may receive other kinds of service coordination. A person needing protective services might have a case worker who is also providing service coordination. Or a person with complex medical needs may be receiving care coordination. This document acknowledges where those other types of service coordination may be relevant, although these other services are not addressed in this first phase of data analysis.

Daily Living

Daily living services include direct support services. Services grouped here include personal assistance, habilitation services, skill development, respite, etc. Depending on the population being served, direct support can include these and other functions:

Self-Care. Assistance with the activities of daily living (ADLs), including eating, bathing, dressing, mobility, personal hygiene; or the instrumental activities of daily living (IADLs), including light housework, laundry, meal preparation, transportation, and grocery shopping; assistance with managing safe and responsible behavior.

Self-Management. Helping a person exercise judgment with respect to their own health and well-being;

Skill Development. Teaching or modeling self-care and self-management skills, physical fitness, behavior management, etc.

Monitoring Safety. Directly or indirectly intervening when a person's health or well-being is at risk.

Financial and Material Assistance

Financial and material assistance includes income supports, public subsidies of room and board, rental assistance, purchases of equipment, or other financial assistance. Usually these services are funded through other programs, through state funds or under waiver programs.

Treatment

Treatment services include a broad range of clinical services. They might include in-home nursing and therapies for people with physical disabilities. Or they could include home based or community mental health treatment services.

Residential Services

Residential services include the publicly subsidized place to live or reside when daily living or treatment services are provided in that setting. Residential services do not include institutional services, defined below.

Institutional

Institutional services include one of the three settings defined as institutions under federal law: nursing facilities, hospitals (for long term stays), and intermediate-care facilities for persons with mental retardation (ICFs-MR).

Relationship between Service Descriptions and Data Definitions

Developing a cross-systems vocabulary can have some limitations when applied to MaineCare claims. While many MaineCare claims can be grouped under these categories, many others are billed differently. For example, service coordination, or case management, under the waiver for older adults and adults with disabilities is billed with all other waiver services, and are not separated out. Daily Living, Treatment and Financial and Material Assistance (in the form of home modifications) are also billed under waivers. The comprehensive waiver for persons with mental retardation includes residential services. The chart to the right attempts to map the relationship between the categories of services and MaineCare expenditure data.

Cross-Systems Vocabulary for Services *Services grouped under these categories….*	Cross-Systems Data Definitions for Services *Can appear as MaineCare expenditures here.*
Service Coordination	Case Management or Waiver (for the Older Adult/Adult waiver)
Daily Living	Community or Waivers
Treatment	Community or Waivers
Financial and Material Assistance	Waivers
Residential	Residential or Waiver (for the MR Comprehensive waiver)
Institutional	Institutional

See the chart on the next page for more information about the data definitions used for categorizing MaineCare Claims Data.

In the second phase of this project, these service categories will be further refined, making it possible to provide more detail within each service category. It may be useful to create subgroups within each population for people in institutions, in residential settings, on waiver programs, and in the community to more fully understand differences in cost drivers across these settings. Other refinements include dividing into two groups those who are eligible for both MaineCare and Medicare, and those who are eligible for MaineCare only.

Defining Population Groups and Services

Not everyone accessing long term services and supports has a continuing need for those services. For example, most people experiencing mental illness do not have a long term need for support. Some people accessing nursing facility services are there only temporarily before returning home.

The Data Group was responsible for specifying the criteria that would be used to define the people who were using long term services and supports within each population group. While not a trivial task, this work is an important first step in redefining long term services and support in Maine and orienting program managers to the full range of needs of the individuals that they serve. The populations and definitions were not limited to those using an HCBS waiver or nursing or ICF-MR facility. People in residential care settings, people receiving certain case management services and people receiving state plan long term care services were also included. This method of defining people who use long term services and supports is a departure from previous methods that typically focused on services as the unit of measurement. The State Profile Team expects to continue to review and refine this methodology and the presentation of the data as part of the second phase of this project.

MaineCare Claims Data – Service Category Definitions[2]	
Service Category	Services Included
Waiver	Maine's four home and community benefits waivers: ▪ Comprehensive waiver for adults with mental retardation (§21) ▪ Community support waiver for adults with mental retardation (§29) ▪ Physically disabled waiver for adults who choose to self-direct (§22) ▪ Older adults & adults with disabilities waiver (§19) Each population group had some claims for services provided through the four waivers. The services grouped under the waiver can include services under the Daily Living category or Treatment category. In the case of the waiver for older adults and adults with disabilities, service coordination is also grouped here.
Community	All in-home support services, population-specific outpatient services, and other services offered in the community that are not waiver or case management services including: ▪ Daily living supports, skills development, day support services (§17) ▪ Assertive community treatment, outpatient psychiatric services, crisis intervention, medication management (§17) ▪ Private duty nursing and personal care services (§96), consumer-directed attendant services (§12), day health services (§26) ▪ Day habilitation (24), school-based rehabilitation (§41) ▪ Rehabilitation for persons with brain injury (§102) ▪ Substance abuse treatment services ▪ Other services offered in the community The type and mix of community services varies by population group.
Case Management	Case management is provided by various agencies and billed under certain programs. Case Management includes intensive case management and community integration services (§17), and targeted case management (§13). Case management for the waiver serving older adults and adults with disabilities waiver is included as a waiver cost.
Residential Services	Residential services (§97) for specific population groups including persons with mental illness, mental retardation, medical and remedial needs, and substance abuse disorders. Members in each population group had claims under different types of residential services. Adult family care (§2) and assisted living (§6) are also included here.
Institutional Services	Institutional services are provided by nursing facilities, intermediate care facilities for person with mental retardation (ICFs-MR), and inpatient psychiatric units.
Medical Services	The Medical Services category includes claims for services used by these members that are primarily acute, medical or routine health services. These services are not specific to a particular program or population. This category includes claims for general inpatient, general outpatient, physician, dental, durable medical equipment, lab, medical transportation, general therapies, etc.

[2] Citations are to sections within 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II.

Some of the issues that were raised and discussed included how and whether to separate out children and adult services and what age to use for defining children's services; how and whether to create a group for children who were 18-21 and transitioning from children's services to adult services; how to categorize services provided to children (*e.g.*, private duty nursing services) when the program was administered by the Office of Elder Services; how to categorize people with physical disabilities who use consumer directed services (in a waiver or on state plan services). Defining long term services for people with Brain Injury was also a difficult task.

A population definition review template was developed to facilitate discussions with each of the core DHHS program areas. The DHHS Office of Quality Improvement conducted meetings with each program office to discuss and define the sub-population of individuals who require long term services and supports and develop specific criteria for use in identifying these populations in the MaineCare Paid Claims Data System.

Criteria for inclusion in a population group include factors such as diagnosis, age, residence and use of certain services. For example, the number of times in a year a person used the psychiatric hospital was one parameter for defining use of long term services for people with mental illness (*e.g.*, two or more psychiatric hospital visits). People in nursing homes had to have a length of stay of more than 30 days to be considered long term service users. In some cases use of a service was further qualified by the need for a particular diagnosis, for example, use of neuro-rehabilitation services and a brain injury diagnosis.

For this first round, the analysis focuses on MaineCare (Maine's Medicaid and SCHIP program) administrative claims data. Paid claims from state fiscal year (SFY) 2008 (7/1/2007-6/30/2008) based on service date use were examined. Items that were not available from claims data (*e.g.*, CAFAS or CHAT scores, state-only funded programs) were not included. Additionally, while service use and costs are fairly complete in claims data, diagnostic criteria may be incomplete. For instance, an individual may have a mental illness but not have a claim filed during a year with a mental illness diagnosis, particularly given that prescription drug claims do not include a diagnosis. Also there are MaineCare costs, settlements, adjustments, rebates and other off-claim adjustments that are not captured in claims data. For these reasons, the population definitions are considered preliminary and will be refined in the second study year.

It is important to note that adults can be categorized and included in more than one population group. Part of this ongoing analysis will be identifying the number of people and the expenditures associated with people served by multiple programs. Nearly 7% of Maine long term services and support users belong to more than one population group.

Nearly 2,000 Adult Users of Long Term Services and Supports (LTSS) Belonged to Multiple LTSS Population Groups in SFY 2008

Number of Population Groups	Number of Members	Percent of Members
One	28,041	93.4%
Two	1,940	6.5%
Three	50	0.2%
Four	2	0.0%
Total	30,033	100.0%

Children were placed only in one group based on the following hierarchy:

- Children with developmental disabilities
- Children with mental illness; and
- Children with a physical disability

On the next page is a summary of the populations and a high level description of the definitions of people using long term services in each of those populations.

High Level Description of Population Definitions[3]

Adults (Age 18+)	
With Mental Illness	Members receiving mental health case management services (§13), or who are in a residential care facility for people with mental illness (§97), or who have two or more inpatient hospitalizations during the year (§46).
Older Adults and Adults with Disabilities	Members residing in nursing homes (§67), residential care (§97) or housing with assisted living services (§6). Members receiving services under the waiver for older adults and adults with disabilities (§19) or private duty nursing (§96) or day health services (§26).
With Physical Disabilities who Self-Direct	Members receiving consumer directed waiver services (§22) or state plan consumer directed personal assistance services (§12).
With Brain Injuries	Use of rehabilitative services (§102); specialized nursing facilities for persons with brain injury (§67); individuals residing in residential care with diagnoses of brain injury;[4] members with inpatient hospitalization over 30 days or eight or more emergency department visits during the year with a brain injury diagnosis.
With Developmental Disabilities	Members in ICFs-MR (§50) or accessed either waiver serving person with mental retardation or autism (§21 & §29); who have MR case management (§13) or MR residential care facilities (§97) or residing in a nursing facility (§67) with an MR diagnosis.
Children (Age 0-17)	
With Developmental Disabilities	Children receiving day habilitation services (§24) services or with a mental retardation diagnosis.
With Mental Disorders	Children using specific mental disorder services including targeted case management (§13), residential treatment (§97), behavioral health services (§65), and 2 or more inpatient psychiatric stays (§46) or crisis stabilization unit stays in the year.
With Physical Disabilities	Children receiving private duty nursing (§96).

Defining Settings

The State Profile Tool is intended to document Maine's distribution of long term services and supports across institutional and home and community-based settings. For the purposes of the data analysis, the settings are defined as follows.

> *Institution.* Services provided in a nursing facility, intermediate care facility for mental retardation (ICF-MR), or inpatient psychiatric unit.
>
> *Residential Setting.* Services provided in a private non-medical institution, adult family care home, or assisted living facility.

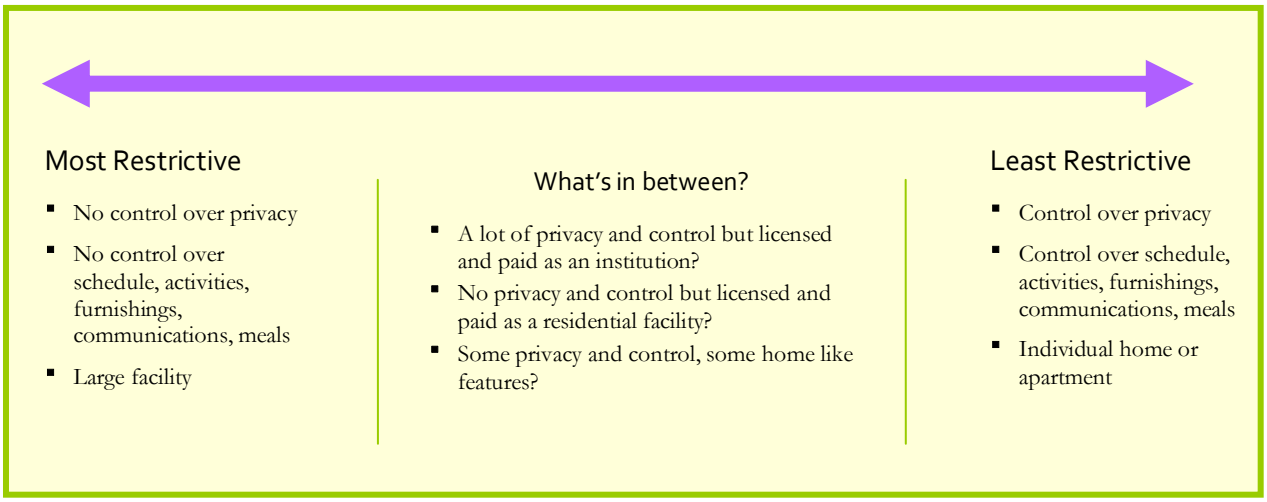
This simple classification can be misleading. Some settings that are licensed and reimbursed as residential services can look and feel like institutions and some "institutions" work very hard to look and feel more like a

[3] Citations are to sections within 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II.
[4] Brain injury diagnosis listing was developed by the Maine Center for Disease Control and Brain Injury Service Unit. Listing is available on request.

home.[5] The Project Team identified several characteristics that would play into whether a setting was more or less restrictive including:

- Restrictions on privacy
- Restrictions on autonomy
- Size (*e.g.,* the number of licensed beds)
- The "look and feel" (*e.g.*, is the setting part of a large campus with multiple levels of care? Or converted residential beds part of a larger nursing facility?)

Distinguishing between the extremes with these criteria can be relatively straightforward, as shown in the figure below.



However, deciding how to characterize what falls in between is more challenging. In APPENDIX A is a draft assessment tool developed collaboratively with the Project Team, with review and input provided by the Stakeholder Advisory Group. This tool includes some preliminary thoughts on how certain setting characteristics can be used to measure "restrictiveness."

In the next phase of this project, the Project Team will explore ways to use these (or a modified version of these) characteristics in assessing existing institutional and residential settings or shaping DHHS' standards for institutional and residential services in the future. Some of the questions under discussion include:

- Are these the right characteristics? Is this a workable tool?
- Can these characteristics be used to evaluate existing residential settings so that DHHS can assess the nature of their institutional and residential services and whether or not their resources are distributed according to their programmatic goals?
- Or should it be a tool used by consumers to evaluate institutional or residential settings?
- Can these characteristics be used to develop a rating system that identifies where the setting falls along a continuum of least to most restrictive?
- Can these characteristics be used to shape DHHS' licensing and purchasing policy across settings?

[5] For example, the Green House Project is an initiative focused on transforming institutional long term care; they envision homes where people enjoy excellent quality of life and quality of care. See http://www.ncbcapitalimpact.org/ for more information.

Although still a work in progress, the tool is included in this document to raise its visibility and invite input and discussion.

Defining System Components

The State Profile Tool Technical Assistance Guide[6] identifies several system components associated with a balanced long term support system. To put some parameters around the system components, key elements were identified with the guidance and input of the Project Team and Stakeholder Group. The rationale for selecting these elements is described in APPENDIX B. Many of the key elements identified represent an ideal that most states have not achieved. However, there was consensus that this analysis provides a foundation for setting goals for the future.

To make the analysis more accessible, findings are summarized using visual flags:

- ● All Key Elements in Place
- ◉ Some Key Elements in Place
- ○ Key Elements Not in Place
- ✕ Not Relevant to Population Group

This review is not meant as a "report card" for DHHS. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems. The Project Team sees this information as the foundation for second phase planning discussions. It is also important to note that not all of the system components are of equal relevance or priority across population groups. Given diversity in the nature of services provided and the progress each program has made in building its community service system, by necessity different programs will prioritize these system components differently. For example, Brain Injury Services is still in its very early stages of development. Some system components are in place and others are a work in progress.

[6] Eiken, Steven. 2006.

System Components

Identifying Key Elements

The following criteria were used to define and identify the key elements of the System Components described in the State Profile Tool Technical Assistance Guide. See Appendix B for the rationale for choosing defining key elements in this way.

Strategic Vision for a Balanced System

- Vision statement
  DHHS has a vision statement for a person centered system of long term services and supports. The vision statement:
  - Defines DHHS' commitment to a long term support system that includes a comprehensive community service system.
  - Is communicated to internal and external audiences.
  - Is used to guide policy and budgeting decisions.

- Monitors progress toward vision
  DHHS measures and monitors its progress toward achieving its vision:
  - DHHS has an agreed upon definition for population groups, services and units of service for reporting and planning of long term services and supports.
  - DHHS has defined measures for monitoring progress.
  - DHHS monitors progress against its measures.

Consolidated State Agency

- Shifting resources
  DHHS has a unified budget for long term services and supports that can be transferred across institutional, residential and home and community based services within a budget cycle.

- Coordinated policymaking
  Programmatic, budgetary, and oversight responsibility for institutional and home and community based services is consolidated with a single point of accountability; or highly coordinated across multiple points of accountability.

- Uses data to plan for services
  DHHS uses data on supply and the demand for home and community-based services to plan for the future and to anticipate and plan for the availability of a qualified workforce.

Single Access Points

- **Information and referral**
  Identifiable organizations provide information and referral on the range of available community and institutional options:
  - The organization is a visible & trusted place for people to obtain information regarding the full range of long term services and supports.
  - The organization accesses a comprehensive and up-to-date resource database for options in service area.
  - Staff provide consistent & uniform information.
  - Access to information and referral is of consistent quality statewide.
  - Providers of general and specialized information and referral play coordinated and complementary roles.

- **Linking with services**
  DHHS uses systematic processes to make sure people understand the full array of services that might be available to them, including housing and residential services, income supports, caregiver supports, etc.:
  - DHHS has a process in place to educate staff, consumers and providers about long term services and supports.
  - Consumers are assisted in identifying appropriate options in the context of their individual needs, preferences, values and circumstances. Access to this assistance is "low barrier," *i.e.*, a person does not have to access case management services in order to find out what service options are available to him or her.

- **Coordinated community and institutional eligibility determination**
  Before a consumer with long term support needs is admitted to an institution, DHHS ensures that the consumer has an opportunity to choose among the full range of options available to that individual.

- **Coordinated clinical and financial eligibility**
  DHHS facilitates the process of determining financial eligibility by providing information and support for completing the MaineCare application for long term care or based on disability. DHHS coordinates the process for determining financial eligibility for long term services and supports with the process of determining clinical eligibility for long term services and supports.

- **Person or family centered planning**
  There is a structured process for a person centered approach to planning:
  - Planning involves the person or family in the planning process.
  - Planning builds on a person's or family's goals, strengths and interests.
  - Planning builds on personal relationships with friends, family and neighbors, as well as paid professionals.
  - DHHS has a process for monitoring progress toward plan goals and updating the plan on a regular basis.
  - Agencies and workers are trained on principles of person centered planning.

- **Tracking waiting lists**
  DHHS has a system for gathering and monitoring waiting list information on key services. DHHS has standards for managing waiting lists, *e.g.,* standards for frequency for updating waiting list information or standards for accepting names on a waiting list.

Institutional Supply

- Privacy and autonomy considered
  Licensing or purchasing standards define requirements for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served. DHHS uses data on the characteristics of its residential options (*e.g.*, information on the types and characteristics of the settings, including level of privacy, level of personal control, and size) to make policy decisions about whether its institutional options meet programmatic goals for most integrated setting.

- Controls on supply
  DHHS has specified criteria that must be met and an approval process for expanding supply of institutional beds (*e.g.*, CON process). DHHS has created incentives for reducing the supply of institutional beds.

Transition from Institutions

- Identifying people for transitioning
  DHHS has a process for identifying people interested in transitioning from an institution.

- Funds transition planning
  DHHS funds transition planning from institution to home. Assistance includes:
  - Assistance with establishing financial and clinical eligibility for services for home and community based services.
  - Coordinating the array of services and providers that will be needed on or shortly after the move.
  - Arranging for transition services that are needed in order to move (*e.g.*, arranging utility hook-up; arranging for home modifications; etc.).

- Funding for one-time transition expenses
  DHHS provides funding for one-time transition expenses (*e.g.*, security deposits, essential furnishings, set-up fees and deposits for utilities, etc.).

Continuum of Residential Options

- Privacy and autonomy considered
  Licensing or purchasing standards define requirements for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served. DHHS uses data on the characteristics of its residential options (*e.g.*, information on the types and characteristics of the settings, including level of privacy, level of personal control, and size) to make policy decisions about whether its residential options meet programmatic goals for most integrated setting.

Continuum of Residential Options, continued

- Range of options
  DHHS provides a range of residential options that includes supported services in an individual's own home; supportive housing, and a range of residential services.

- Up-to-date information about available options
  Consumers can access a database with accurate and up-to-date information about affordable and accessible housing and residential options that includes search fields for: target population; current vacancies; unit cost or rents; acceptance of rental assistance; geographic location; physical accessibility.

Long Term Services and Supports Infrastructure Development

- Case management
  DHHS provides case management services for this population group.

- Develops workforce to meet needs
  - DHHS supports training for workforce to meet needs of population group.
  - DHHS addresses workforce supply.

- Support for informal caregivers
  DHHS has policies and programs that support informal caregivers, including respite, information and referral, support services, or education and training.

- Uses evidence based practices
  DHHS uses evidence based practices in the delivery of services.

- Stakeholders participate in planning for services
  DHHS involves stakeholders in identifying service gaps and identifying and implementing new service models.

Consumer Direction

- Individualized budget
  DHHS has the building blocks for consumer directed services: DHHS can build a portable individual budget for services using a standardized method for allocating resources based on individual need for services.

- Option to hire own workers
  The consumer has an option to hire their own direct care workers.

Consumer Direction, continued

- Option to purchase goods and services
  The consumer has the option to manage his or her own budget and purchase goods and services outside the standard service package.

Quality Management

- Quality management plan
  DHHS develops and uses a quality management plan for each population:
  - The roles and responsibilities for overseeing quality are clearly defined.
  - The quality management plan is updated periodically.

- Quality measurement
  DHHS uses quality measurement information to inform program performance and system improvements:
  - Quality indicators have been identified.
  - Quality measures are reviewed on an ongoing basis.

- Consumer surveys
  DHHS routinely asks consumers about their satisfaction with services and supports (*e.g.*, consumer surveys are conducted).

Data Sources

MaineCare Claims Data

Because the availability of data for other programs is variable, for this first round expenditures and utilization is based on MaineCare (Maine's Medicaid and SCHIP program) administrative claims data only. For this baseline analysis, paid claims from state fiscal year (SFY) 2008 (7/1/2007-6/30/2008) based on service date use were examined.

In the next phase of this project, the State Profile Tool Project Team will learn more about Maine's long term support system by:

- Refining population definitions, based on claims analysis of currently defined groups; for those dually eligible and not dually eligible for MaineCare and Medicare; and by setting.
- Looking at overlapping adult populations
- Looking at cost drivers for each population
- Looking at funding through other programs including state-funded, Medicare and child welfare.

Document Review

Program, service and system component descriptions were informed by reviewing the following documents:

- Maine statutes, regulations and pertinent litigation documents.
- DHHS legislative studies and reports; ad hoc reports and recommendations, legislative briefing documents, grant applications, grant and project reports.
- DHHS performance monitoring reports
- Policy journal articles and books
- DHHS, provider, consumer and advocate websites
- National data sources

Citations to specific documents are included in the profile.

Meetings and Interviews

Other information was gathered through Project Team, Data Group and Stakeholder Advisory Group meetings; from key informant interviews; and from stakeholder meetings related to Maine's Systems Transformation Grant.

National Data Comparisons

The presentation of the data used definitions and formats representing a new way of aggregating and analyzing long term service users and expenditures in Maine. The results are not easily compared to national data commonly referenced (*e.g.*, compilations of Medicaid long term case expenditures produced by Thomson Medstat). To avoid confusion for the different audiences reading this document, those data were omitted here.

State Profile

Overview

Maine has made much progress in improving the balance between institutional and home and community based services. Its history of de-institutionalization has been matched by a commitment to building systems of community-based services and supports. However, the continued sustainability of these systems must be considered in light of their relationship to overall MaineCare expenditures – in 2008, expenditures for long term service users were approximately 62% of total MaineCare expenditures. Maine's aging population, relatively high poverty rates, and the struggle to balance revenue against expenditures will increasingly add pressure on the system.

This profile provides a cross-system view of the gains Maine has made, as well as needs common across programs.

System Strengths

DHHS long term support system has many strengths. DHHS has:

- Shifted its focus from de-institutionalization to diverting people from institutional services whenever possible.
- Improved coordination across programs, through its Integrated Management Team and co-location of policymaking and frontline staff.
- Placed a heavy emphasis on person or family centered services, in most programs.
- Invested in quality management and incorporated evidence based practice.

Policy Directions

This cross-systems view provides an opportunity to consider some cross-system policy decisions. For example, is it possible to:

- Establish a common vision for the appropriate distribution of resources across settings, to guide resource allocation decisions going forward?
- Establish common criteria for defining "least restrictive" and "most restrictive" settings, so that DHHS resources are applied according to its vision?
- Set common expectations and standards for person or family centered services and consumer-directed services?
- Develop common strategies for addressing the impact of an aging population on the long term support system across population groups?

Cross-System Capacity

Several programs would benefit from common investments including:

Information and Referral and Assistance

- Ensuring that Maine's array of general and specialized information and referral resources are leveraged to their maximum advantage to provide needed information and referral of consistent quality statewide.

- Providing a higher level of assistance when people need to understand the service options that might be available to them.

Better Support for MaineCare Applicants
- Improved integration of MaineCare eligibility and program eligibility processes, especially when these two eligibility processes are interconnected (*i.e.,* when a level of care determination is required for a waiver, for "Katie Beckett" eligibility, or nursing facility admission).
- Assistance preparing MaineCare applications for long term care and when eligibility is conditioned on proof of a disability.

Waiting Lists
- Developing consistent standards and strategies for managing waiting lists at the provider and systems levels.

Housing Registry
- Leveraging the housing registry currently being built to include residential options across programs.

Workforce
- Looking for opportunities to align training and recruitment and retention strategies for direct support workers.

Enhancing Consistency in Quality Management Strategies
- Leveraging the quality management capacity across programs to foster greater consistency.
- Improving the consistency and availability of data across programs.

Areas for Further Examination

A number of issues requiring further examination were identified. Some of these include:

- The need to evaluate the effectiveness of diversion efforts.

- The need for more systematic processes for identifying people who might be interested in transition.

- Whether or not programs have the right distribution of services across MaineCare and state funding, ensuring access for people who need services but are not eligible for MaineCare because of financial eligibility requirements.

- Whether or not DHHS should define a policymaking "home" for children with physical disabilities.

Maine's Long Term Support System in Context

Maine's Long Term Support System in Context

Maine has made much progress in improving the balance between institutional and home and community based services. Its history of de-institutionalization has been matched by a commitment to building systems of community-based services and supports. The continued sustainability of these systems must be considered in light of their relationship to overall MaineCare expenditures – in 2008, expenditures for long term service users were approximately 62% of total MaineCare expenditures. Maine's aging population and low income levels will increasingly add pressure on the system.

History of Reform and Systems Change

De-Institutionalization & Diversion

Maine has been one of the leaders in de-institutionalization. Starting in the 1950s, Maine began reducing the number of residents served in its only state-operated institution for persons with developmental disabilities. This process accelerated in the late 1970s and finally, in 1996, Maine became one of only three states with no state-operated institution for this population group. Beginning in the 1970s, Maine also significantly decreased the number of people in its two state operated psychiatric hospitals, shifting the primary focus of these hospitals to short term acute care and away from long term residential services. In the 1990s, Maine introduced a requirement that anyone seeking admission to a nursing facility be determined eligible based on a standardized assessment conducted by an independent assessing agency. For children, after a peak of 260 children in residential out-of-state placements in 1998, Maine had successfully reduced that number to 17 in 2008. The timeline on the next page highlights some of these developments.

Community Services

At different points in its history, DHHS has been ahead of the curve in building innovative community services. It has been a leader in promoting consumer direction, streamlining eligibility processes, promoting community inclusion for people with disabilities, and incorporating peer support and recovery into mental health services. Maine also took a very progressive approach in responding to the Olmstead decision, convening a planning body comprising consumers representing a cross-section of population groups and state staff representing five departments. Community services are described in detail in later sections.

Systems Change Initiatives

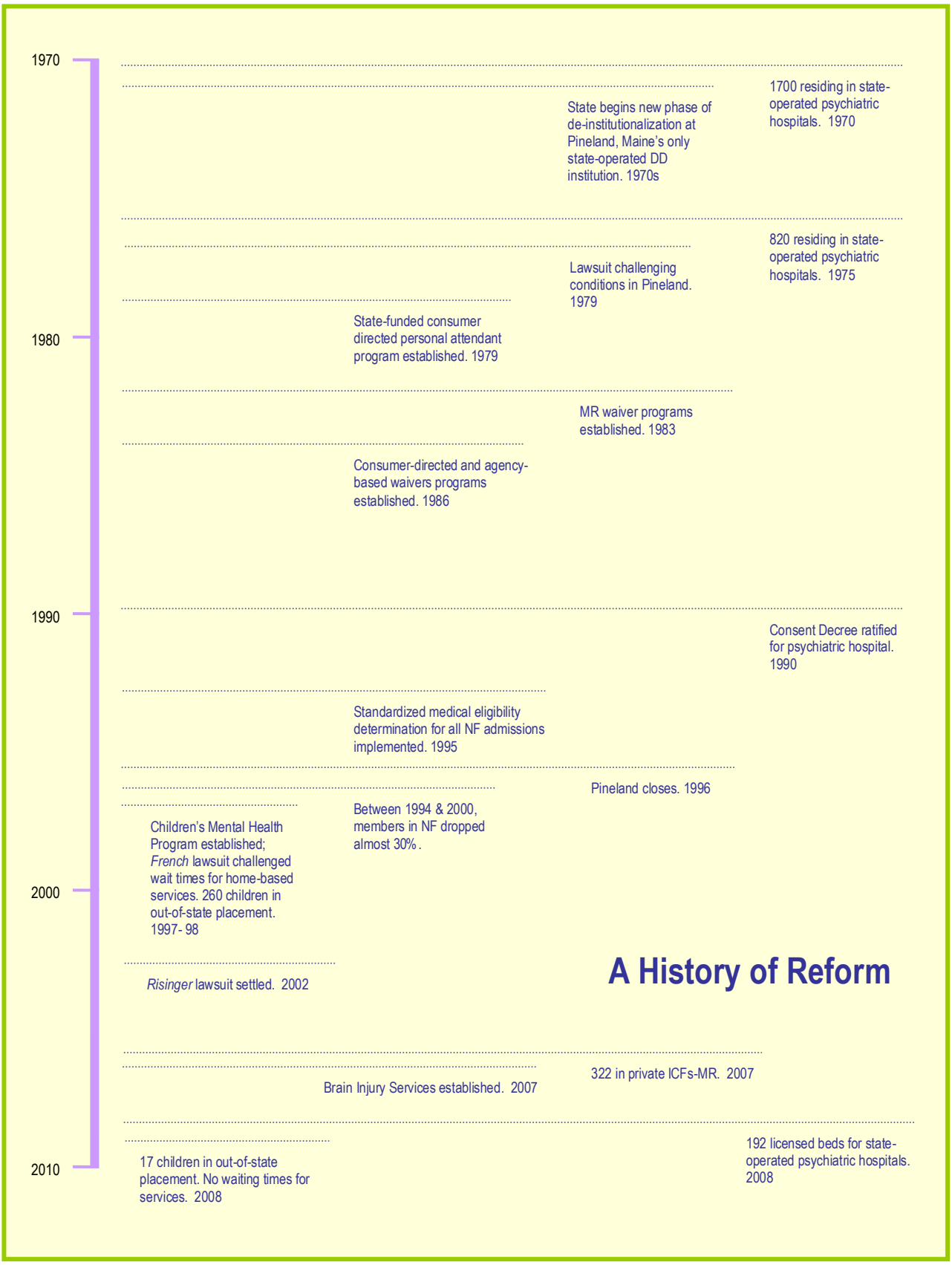
Maine has leveraged a number of Real Choices Systems Change grants and other funds to improve its long term support system.

Real Choices Systems Change (2001). Project activities related to person centered services, quality of services, access to services, and data integration.

Maine Aging and Disability Resource Centers (2003). DHHS piloted an ADRC in three of Maine's five area agencies on aging.

Workforce Demonstration (2003). DHHS tested the impact of two interventions (health care coverage and "employer of choice" workplace changes) on recruitment and retention of direct service workers in community long term support programs.

Money Follows the Person (2003). DHHS developed a published rate structure as foundation for building consumer directed for persons with mental retardation and autism. Tested an assessment tool for predicting successful transition for persons with brain injury residing in residential care facilities.


1970
1980
1990
2000
2010
1700 residing in state-operated psychiatric hospitals. 1970
State begins new phase of de-institutionalization at Pineland, Maine's only state-operated DD institution. 1970s
820 residing in state-operated psychiatric hospitals. 1975
Lawsuit challenging conditions in Pineland. 1979
State-funded consumer directed personal attendant program established. 1979
MR waiver programs established. 1983
Consumer-directed and agency-based waivers programs established. 1986
Consent Decree ratified for psychiatric hospital. 1990
Standardized medical eligibility determination for all NF admissions implemented. 1995
Pineland closes. 1996
Between 1994 & 2000, members in NF dropped almost 30%.
Children's Mental Health Program established; French lawsuit challenged wait times for home-based services. 260 children in out-of-state placement. 1997- 98
A History of Reform
Risinger lawsuit settled. 2002
322 in private ICFs-MR. 2007
Brain Injury Services established. 2007
192 licensed beds for state-operated psychiatric hospitals. 2008
17 children in out-of-state placement. No waiting times for services. 2008

Independence Plus (2003). DHHS developed information, training materials and other tools for persons with mental retardation and autism and their family members to support their participation in consumer directed services. (Unfortunately, funding for the consumer directed waiver program was lost due to budget constraints.)

Improving Quality for People with Disabilities in the Community (2003). DHHS developed tools to support quality management for home and community-based services.

Comprehensive Employment Options (CEO). Maine has a CEO grant under the TWWIIA-funded employment initiatives. The CEO work is building on Maine's successful Medicaid Buy-In program for workers with disabilities.

Systems Transformation (2005). Maine is working to improve access to services, improve consumer choice and control and increase access to housing services.

In addition to these grants, Maine has also accessed a number of other grants, including funding from SAMHSA to develop a trauma informed system of care (the THRIVE project) and integrate mental health and substance abuse services for persons with co-occurring disorders (the COSII project).

Reorganization

The 2004 merger of the Department of Human Services (DHS) and the Department of Behavioral and Developmental Services (BDS) has enabled greater coordination across programs including:

Integrated Management. The Deputy Commissioner for Integrated Services convenes the Integrated Management Team (IMT), comprising the office directors for each program, the Office of MaineCare Services, the Center for Disease Control, the Division of Licensing and Regulatory Services, and DHHS' regional directors. Operationally, the IMT is responsible for coordinating policymaking and budgeting, and leading implementation of the department wide strategic priorities.

Strategic Priorities. DHHS has identified a series of strategic priorities (see the box on the next page) for improving its service system, including moving beyond siloed systems of services.[7]

Systems Management and Integration

DHHS has also taken steps to standardize processes, integrate care, and impose more controls on utilization:

Standardization. The development of enterprise information systems and an emphasis on performance measurement and accountability has imposed greater standardization on the process of determining eligibility and providing services.

Integration of Care and Care Management. The MaineCare program has contracted with a care management provider to provide care management services to those at risk for high utilization. The Office of Substance Abuse has focused on integrating care for persons with co-occurring conditions.

Utilization Review for Behavioral Health Services. DHHS has taken its first steps toward implementing a system of managed care for behavioral health services. Beginning in 2007, DHHS entered into a contract with an Administrative Service Organization (ASO) to provide eligibility verification, prior authorization and utilization review services. The ASO also supports a management information system to facilitate department decision making, client tracking, reporting, and quality management functions.

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[7] Maine Department of Health and Human Services. 2009. *In Focus Reference Book.*

Lean Process Improvement. DHHS uses a set of trained public sector internal consultants to analyze business process to reduce waste, add value and reduce delivery time.[8] Lean intervention has been used to review coordination of the clinical and financial eligibility determination processes for home based care and institutional services; it has been used to review the steps involved for youth transitioning to adult services.

Leadership & Vision

DHHS Mission & Vision. As part of the 2004 reorganization, the Legislature defined DHHS' mission[9] and DHHS defined its vision. In addition, DHHS has defined key components of its strategic plan for further refining its organization and operations.

Role of Consumers and Other Stakeholders. In recent years, the voice of adults with mental illness has become stronger through a formal network of advisory councils and through advocacy organizations. Adults with developmental disabilities have a statewide network of self-advocacy organizations. Parents and children's advocates have played an important role in changing the landscape of children's services, both by participating in policymaking and providing support to other parents. For other population groups, legal advocates, ombudsman programs, and providers often play a strong role advocating on behalf of consumers, but the consumers themselves do not appear to be as well-organized.

Legislature. The Legislature has played an important role in the rebalancing of Maine's long term support system. Community services, person centered planning, independence, personal rights have all been embedded in different parts of DHHS authorizing legislation. As a general rule, however, the Legislature does not speak with single voice when it comes to rebalancing. Legislators tend to play a mediating role among interest groups and constituents, rather than driving a particular agenda. Some legislators are themselves providers or are members of a provider board. In addition, individual legislators often contact DHHS on behalf of a particular constituent. These interventions might be to expedite the process; they can also relate to the needs of people who don't fit neatly into the categories of program eligibility. In general, however, these constituent calls do not necessarily drive DHHS policy toward a more or less integrated service array.

Department of Health and Human Services

Mission: The mission of the department is to provide health and human services to the people of Maine so that all persons may achieve and maintain their optimal level of health and their full potential for economic independence and personal development.

Vision: Maine people living safe, healthy, and productive lives.

Strategic Priorities

- DHHS supporting infrastructure is easily accessible, well-integrated and uses best practice.
- Health and human service systems are easily accessible, well integrated and use best practices.
- Caring, responsive, and well-managed staff work in a safe, efficient and effective culture.
- DHHS is a caring, responsive and well-managed organization that communicates effectively.

Over the years, the Legislature has created a number of study commissions or requested reports from DHHS that relate to improving services for people with disabilities. Some recent examples include:

- Requiring DHHS to develop an ongoing assessment process for adult MaineCare members living in out-of-state facilities to identify people who could benefit from a less restrictive setting.[10]
- Requiring DHHS to develop a comprehensive plan for brain injury services.[11]
- Requiring DHHS and the Department of Labor to jointly develop a statewide implementation plan for a waiver that provides supported employment to persons with developmental disabilities.[12]

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[8] Ibid.
[9] 22-A MRSA §202(1).
[10] Chapter 61, *Resolve, To Ensure Proper Levels of Care for the Elderly and the Disabled* (2007).
[11] Chapter 105, *Resolve, To Promote Community Integration for Individuals with Brain Injury* (2007).
[12] Chapter 101, *Resolve, To Create Improved Employment Opportunities for People with Disabilities* (2007).

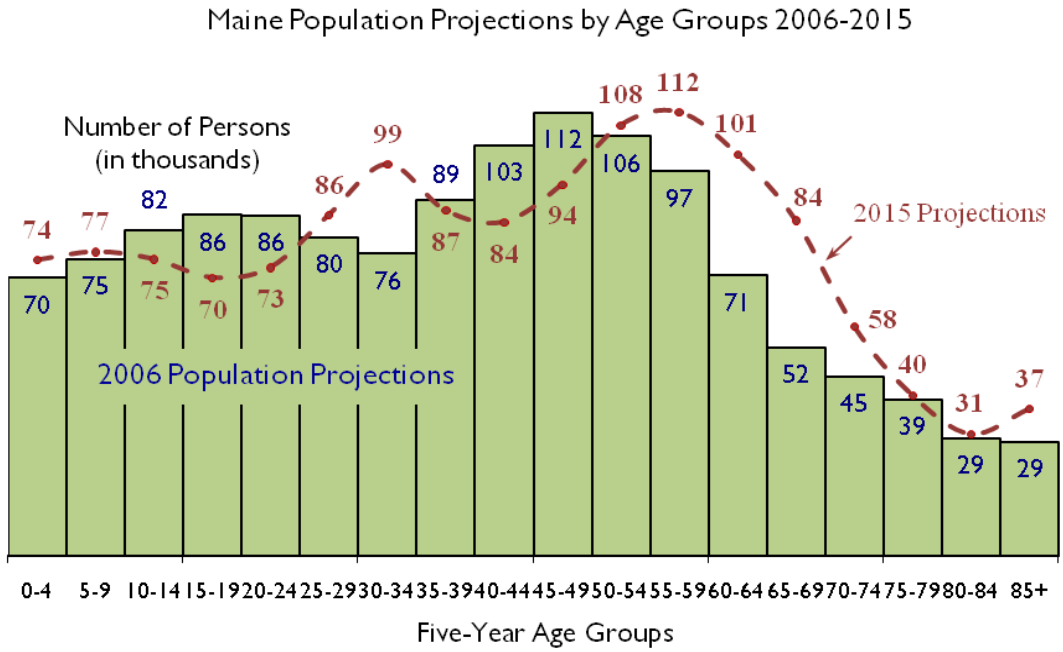
- Creating a commission to "create a coherent blueprint to ensure the sustainability of long term home-based and community-care options" for elders and adults with disabilities.[13]
- Requiring DHHS to review eligibility criteria for fairness.[14]
- Requiring DHHS to study direct care workers in state-funded and MaineCare funded programs, in conjunction with the Department of Labor.[15]

The Legislature also creates oversight committees and consumer advisory councils.

The Judiciary's Role. The judiciary has played an important role in the rebalancing of services in Maine. A consent decree governing adult mental health services has been a major policy driver, shaping client rights, the development and delivery of services, performance measurement and other aspects of the delivery system. Similarly, the Community Consent Decree governs the community services provided for people who once resided in Pineland, an institution for people with developmental disabilities. Two class actions suits have reshaped the delivery system for children's services; significantly reducing wait times for services. Other litigation resulted in new standards for accessing case management services for adult developmental services.

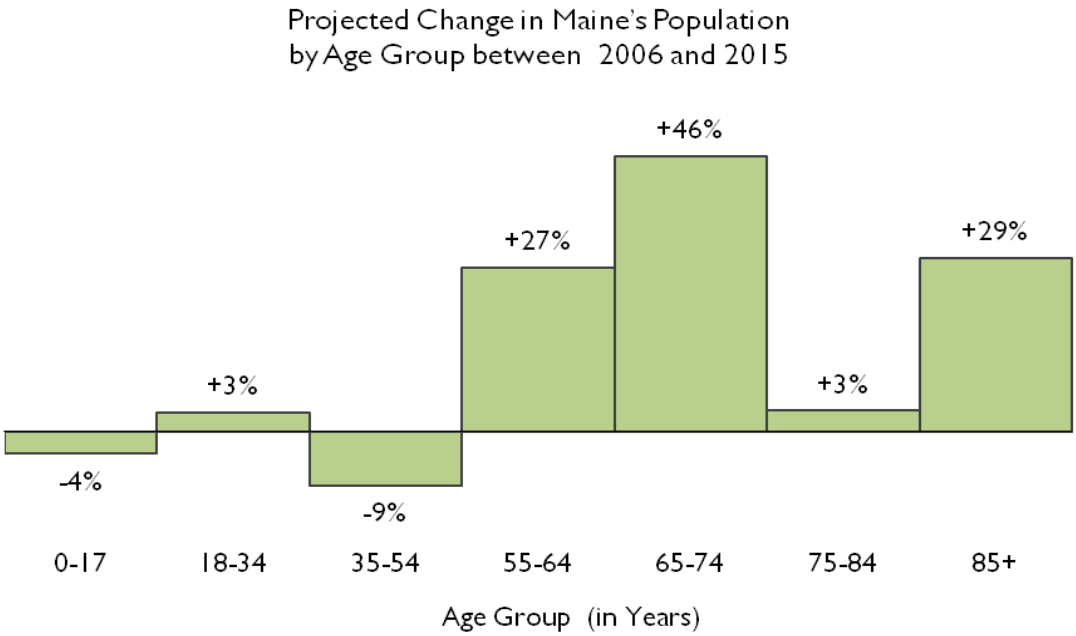
Maine's Demographics

The demographics of Maine's population will continue to drive the use of long term care services in Maine. In 2007, Maine ranked fourth in the nation with the percent of people over age 65 (14.8%). By 2030, Maine will have the second highest percentage (26.5%) of people age 65 or over. Using the median age of the population as a measure, Maine is already considered the "oldest" state in the nation. In the near term, Maine will see the largest growth in the population ages 55-65 and 65-74.

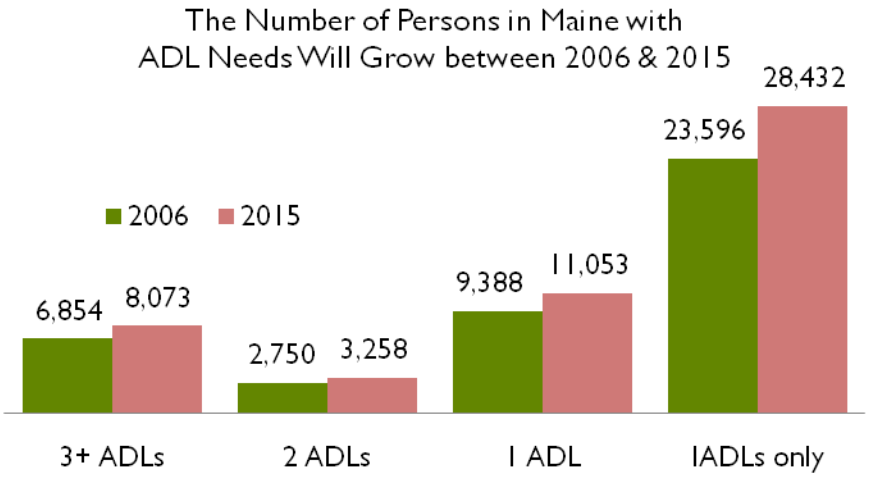


Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005. 1/12/09.

[13] Chapter 209, *Resolve, To Create the Blue Ribbon Commission to Study the Future of Home-based and Community-based Care* (2008).
[14] Chapter 58, *Resolve, To Review Statutes, Rules and Policies Regarding Mental Retardation, Pervasive Developmental Disorders and Other Cognitive and Developmental Disorders* (2007).
[15] Chapter 194, *Resolve to Improve Retention, Quality and Benefits for Direct Care Health Workers* (2006).

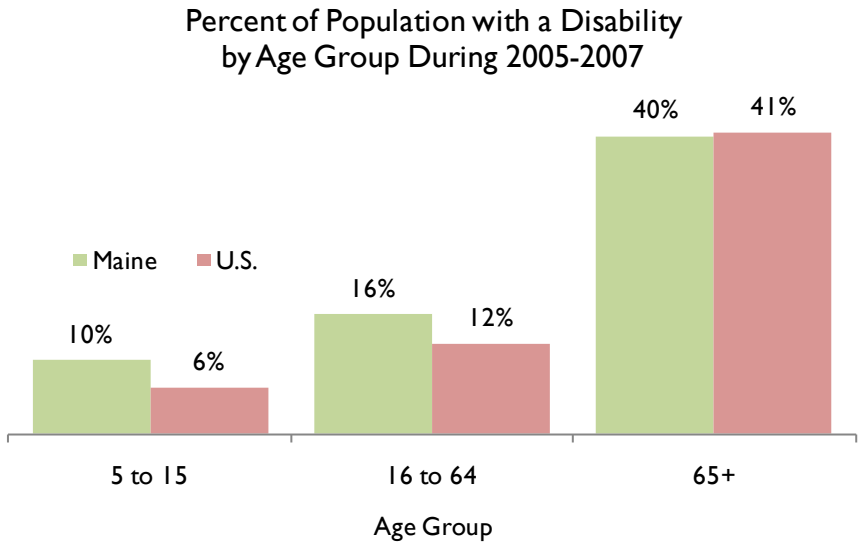


Source: U.S. Census Bureau, Population Division, Interim State Population Projections, 2005. 1/12/09.

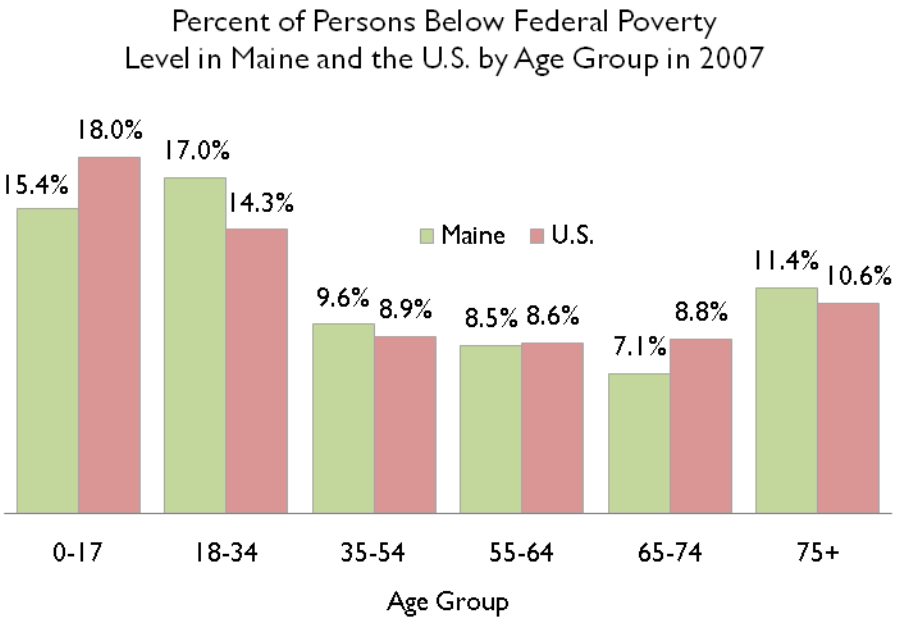


Source: The Lewin Group and the Muskie School of Public Service. 2008. Projections of State and County Level Long Term Care Need and Use in Maine, 2006-2015.

The age group 65-74 is expected to increase 46% from 2006 to 2015. The population over 85 is also expected to increase by almost a third. The increase in the older cohorts of the population will be accompanied by an increase in the number of people in the general population who need help with instrumental activities of daily living (*e.g.,* meal preparation, shopping, housekeeping, etc) and activities of daily living (*e.g.,* assistance with bathing, using the toilet, walking etc). The greatest increase in the short term is projected to be in the number of people needing assistance with the more routine activities of daily living (*e.g.,* IADLs).



Source: U.S. Census Bureau, 2005-2007 American Community Survey

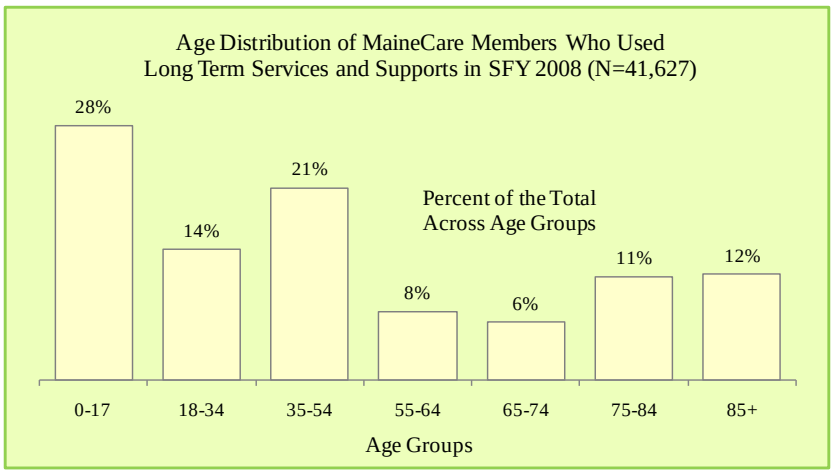


Sources: U.S. Census Bureau, American Community Survey, 2007 Public Use Microdata Sample for Maine, and U.S. Census Bureau, Current Population Survey, 2008 Annual Social and Economic Supplement.

Other drivers of long term service use are the number of people with disabilities. Maine has a higher percent of people with a disability for those under 65; for those over 65, Maine's rate of disability is comparable to the U.S. The number of people who are below poverty is another driver of the use of MaineCare services.

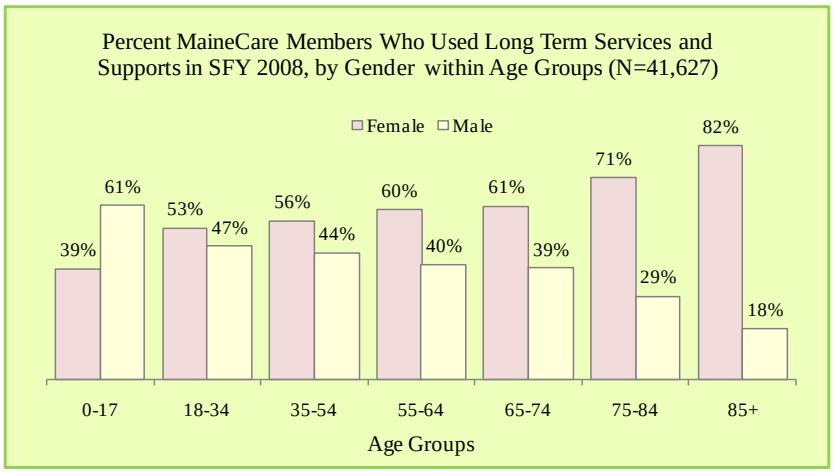
Long Term Service Use and Cost in Maine

In 2008, expenditures for long term service users were approximately 62% of total MaineCare expenditures. Users of long term services and supports include children and adults across the age span. The following table shows the distribution of long term service users by age group and sex.



Long term service users span all age groups:

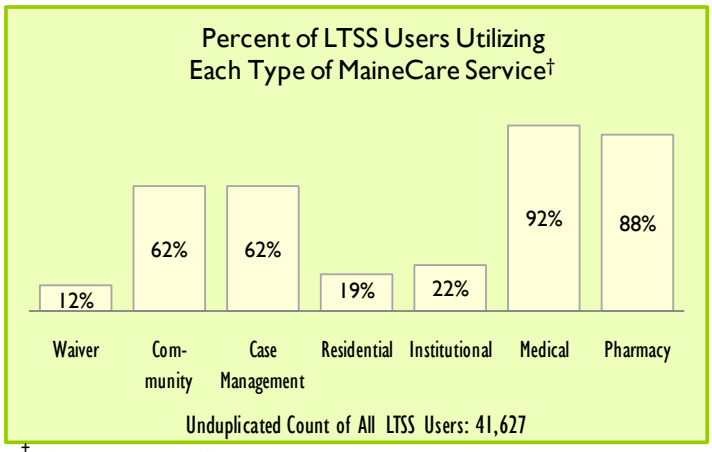
- 28% of users are 17 or younger
- 29% of users are 65 years or older
- 29% of users are between 35-64



All age groups except children have a higher percentage of females:

- 61% of those accessing children's services are male
- 82% of those 85 and older are female

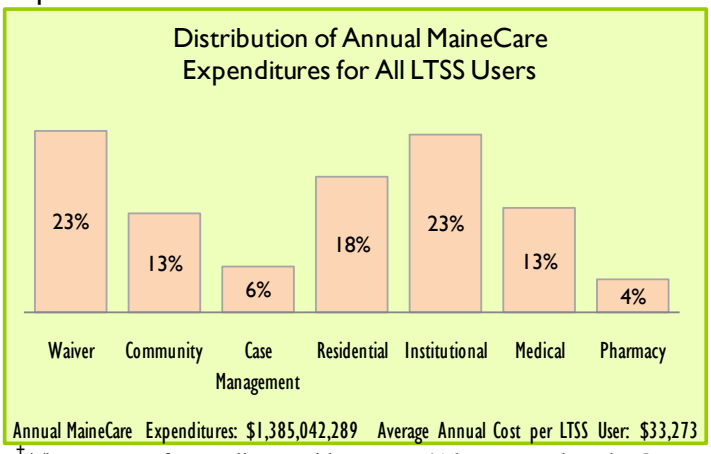
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- Of all long term services and supports users, 62% are accessing some kind of community services.
- Similarly, 62% are accessing some kind of case management services.
- 92% of long term services and supports users received medical services and 88% used pharmacy services.

Expenditures



† The percent of expenditures add up to 100% because each MaineCare dollar was attributed to a single service category.

- Waiver and institutional services are the largest categories of expenditures for all long term services and supports users.
- Residential services represent the third largest cost category.

DEFINITIONS AND DATA

These tables represent utilization and expenditures for the unduplicated total of long term service and support users.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data.

This presentation of data uses new definitions and formats, representing a new way of aggregating and analyzing long term service users and expenditures in Maine. The results are not easily compared to national data commonly referenced or to other presentations of data that have historically been used in Maine.

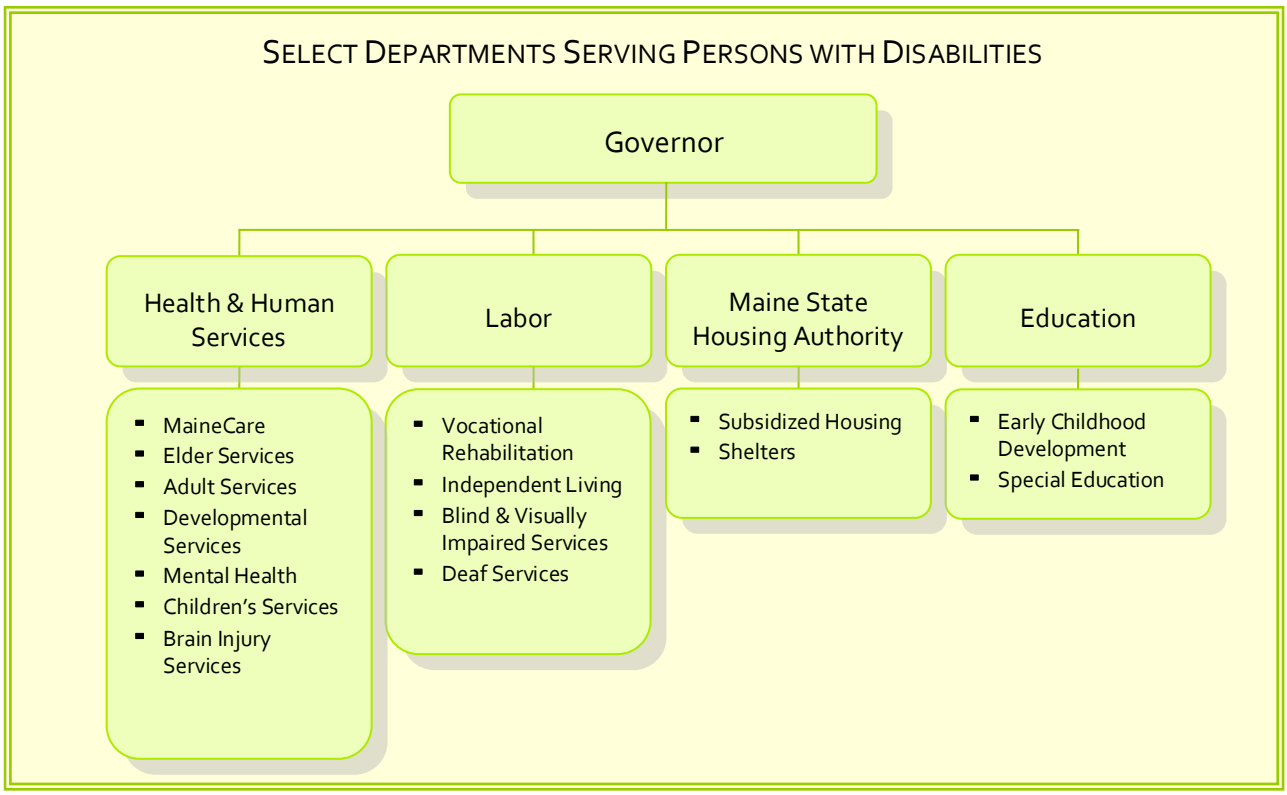
See PROCESS AND APPROACH for more detail on how service categories are defined.

Systems Administration & Management

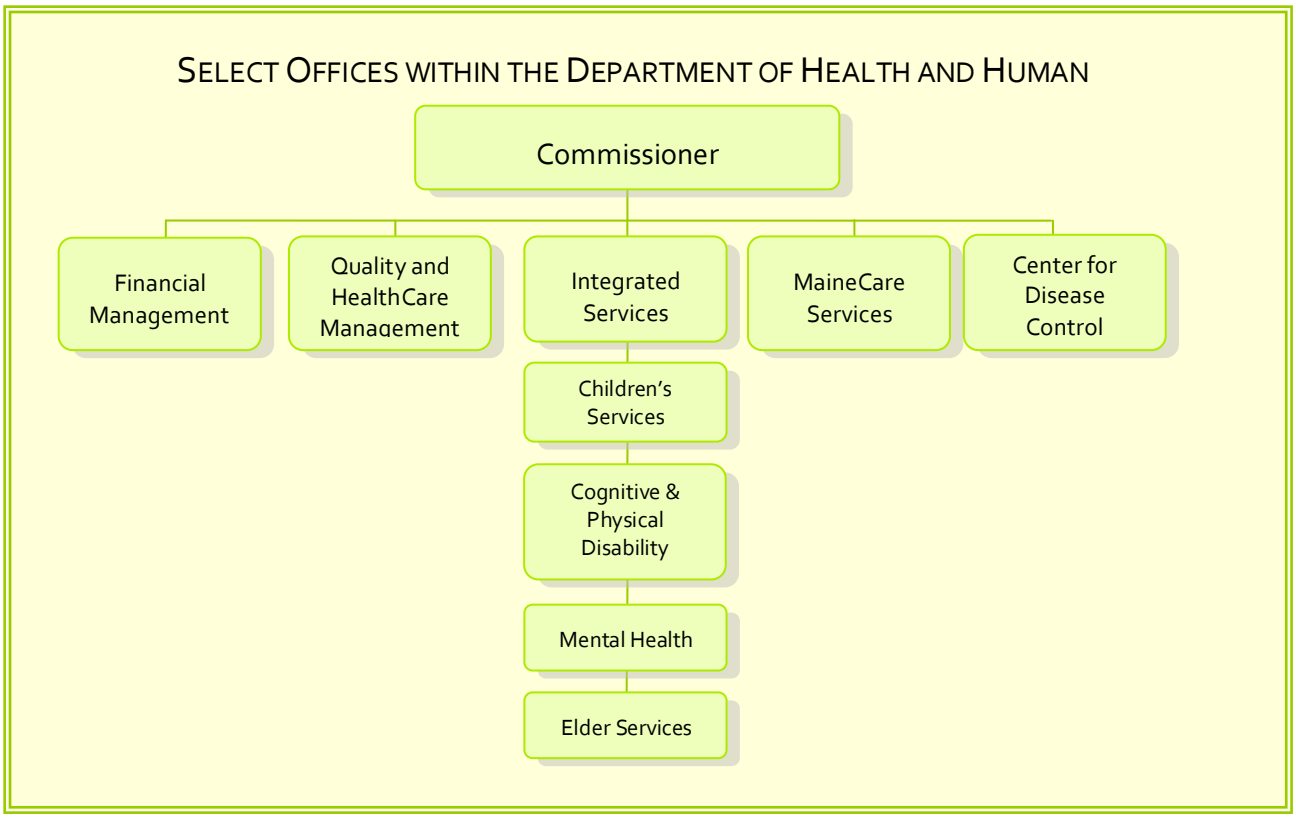
Systems Administration & Management

Within Maine state government, a number of cabinet level departments can touch the lives of persons with disabilities. The department with the largest role, the Maine Department of Health and Human Services (DHHS) is the umbrella department for the majority of long term support and service programs for persons of any age having a disability. The Department of Labor oversees the vocational rehabilitation program and Maine's independent living services and centers. The Maine State Housing Authority administers programs that serve people with disabilities, including subsidized housing programs and programs for people who are homeless. And the Department of Education is responsible for administering early childhood and special education programs across school systems. See OTHER SERVICES for more on the role of these other departments.

The Department of Transportation also plays a role in coordinating transportation policy to improve access for persons with disabilities. DHHS also coordinates with the Department of Corrections, which provides behavioral health and other services to people within their jurisdiction and facilitates reentry into the community for people needing services and supports when they transition out of prisons.



Within DHHS, direct health and social service programs are under the direction of the Deputy Commissioner for Integrated Services. In addition, the Deputy Commissioner is responsible for overseeing the operation of Maine's state run institutional services. The Office of MaineCare Services is responsible for overseeing Maine's Medicaid program, setting policy, assuring compliance and paying claims. The Deputy Commissioner for Quality and HealthCare Management oversees key elements of systems infrastructure, including important health care management contracts, the division for licensing and regulatory services, quality improvement, and information technology. In addition to the offices represented in the chart on the next page, the Deputy Commissioner for Integrated Services also oversees income support programs, substance abuse treatment, and other functions related to direct health and social services.



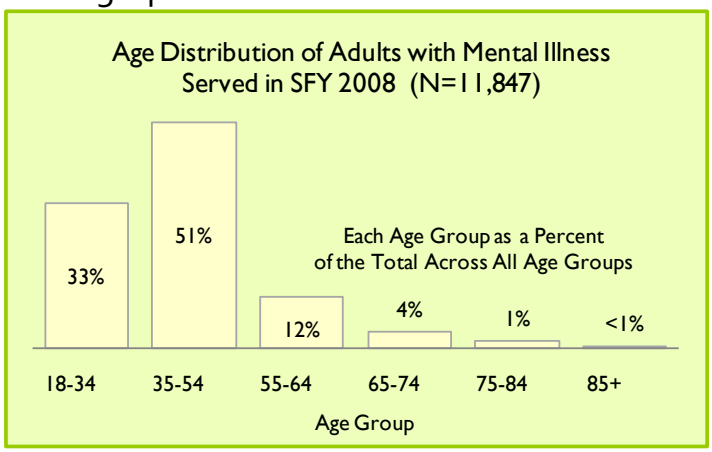
PROGRAM OFFICE, POPULATION GROUP AND LOCAL ADMINISTRATION		
State Agency	Population Group	Local Agents
Adult Mental Health Services	Adults with serious & persistent mental illness primarily	Regional AMHS & community providers
Elder Services	Elders and adults with disabilities	Statewide independent assessing agency, statewide care coordinating agency, community providers
Adults with Cognitive & Physical Disability Services (OACPDS)	Adults with physical disabilities	Statewide independent assessing agency, statewide care coordinating agency, personal assistance workers
	Adults with mental retardation & autism	Regional OACDS & community providers
	Adults with brain injury	Community providers
Child & Family Services (OCFS)	Children with behavioral health needs	Regional OCFS & community providers
	Children with developmental disabilities	Regional OCFS & community providers
Office of MaineCare Services	Children with physical disabilities	Home health agencies[16]

[16] Children who use the Family Provider Services Option (a consumer directed option available to elders and adults) access this service through the elder and adult statewide home care coordinating agency. See OLDER ADULTS AND ADULTS WITH DISABILITIES.

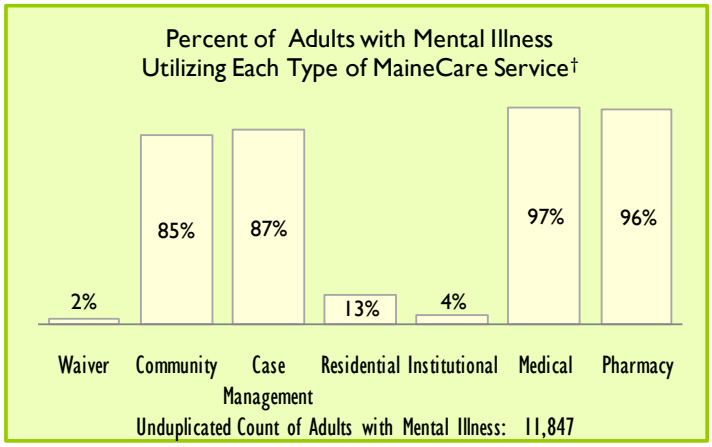
Adults with Mental Illness

Adults with Mental Illness

Demographics



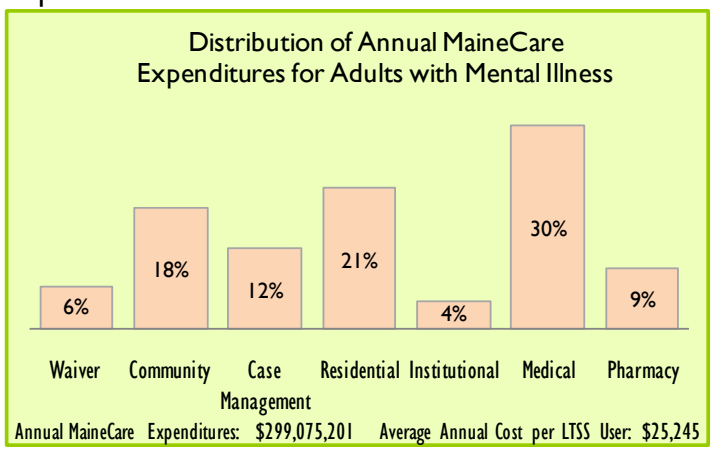
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- 85% of people in this population group accessed community based services.
- 97% of people in this population group accessed some form of medical services and 96% accessed pharmacy services.
- 13% of people in this population group accessed services in residential settings.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- 30% of MaineCare expenditures for this group are related to medical care services.
- 21% of MaineCare expenditures are related to residential services.

System Strengths

Person Centered Services. While DHHS believes there are opportunities for improvement, it has defined standards for implementing individualized planning built into purchasing and licensing requirements as well as its training curricula.

Transition Services for People being Discharged from a Psychiatric Hospital. DHHS builds discharge planning into the service planning for psychiatric hospitalization. Community integration workers are available to help with transition and some funding is available for one-time transition costs.

Residential Options. DHHS residential services are predominantly available in settings with less than nine beds. DHHS is increasingly focused on providing supportive housing services in a home or apartment of the individual's choosing.

System for Stakeholder Involvement in Service System Design and Implementation. While the roles of its Community Service Networks and its statewide networks of Consumer Councils are each still evolving, they both offer the opportunity for systematic stakeholder involvement in delivery system and service design and implementation.

Areas for Further Examination

Access to Services. There are barriers to information sharing and steps are often repeated for determining clinical eligibility for different types of services. The process of applying for MaineCare services can be slowed when documentation of a disability is required.

Consumer Direction. While consumer direction is not as common for mental health services as it is for other population groups, there is growing precedent for offering people with serious mental illness the opportunity to direct their own services.

Aging Population. As Maine's population ages, DHHS will need to evaluate its readiness to serve older adults with severe and persistent mental illness.

Medicaid Versus State Funding for Services. DHHS now relies heavily on MaineCare to fund services for this population group, raising questions about access for those who are clinically eligible but not financially eligible for services.

DEFINITIONS AND DATA

Adults with Mental Illness were defined as those members receiving community integration services (*i.e.* people with severe and persistent mental illness), or were in a residential care facility for persons with mental illness, or had two or more inpatient hospitalizations during the year.

> NOTE: The data definition used for this population group may be refined. The number of members represented in this data is larger than Program staff expected. For this first analysis, members in this group were defined by use of services over the course of one year; program staff would like to examine use of services over multiple years.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. Adult members may be in more than one office population; therefore, adult office populations should not be added. Adult totals shown here have been aggregated as distinct counts and dollars.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

Adults with Mental Illness

Most people experiencing mental illness do not need long term services and supports. For some, however, mental illness can also have major life consequences, causing a loss of employment, independence, and community roles. In Maine, long term services and supports are targeted to those with severe and persistent mental illness, *i.e.*, persons with a major mental illness or a personality disorder who experience certain functional consequences of their diagnosis (*e.g.*, homelessness, incarceration, risk of institutionalization).[17]

Mental illness can be episodic in nature, meaning that a person may have an acute need for services at different points in time. So, in addition to offering long term services and supports, the mental health system also needs to be both flexible and responsive to the acute need for services and coordinate across both. In addition, with a changing understanding of mental illness, the service system must provide therapeutic and person centered services that promote recovery as an achievable goal.

Adding to the complexity of providing comprehensive mental health services is the need to also address physical health conditions. DHHS analysis shows that persons with serious mental illness in the MaineCare population were more likely to have co-occurring physical health conditions than other MaineCare members.[18] Substance abuse addictions are another common co-occurring condition, requiring coordination and integration across systems of care. Historically, physical health care, treatment for addictions, and mental health treatment have been provided in silos. Integrating across these different delivery systems means overcoming hurdles in both policy and practice.

Program and Services

In the last 40 years, Maine's mental health system has evolved from long term institutional services to a community health system, with psychiatric hospitals designed to provide only acute care. Maine has two state-operated psychiatric hospitals, one in Augusta and the second in Bangor. Up until the early 1970s, these hospitals provided long term services for persons with mental illness. At that time, in the space of five years, the Augusta Mental Health Institute (AMHI) reduced its census from 1500 to 350.[19] Similarly, Maine's Bangor facility went from 1200 in 1970 to 470 in 1974.[20] Following this period of rapid de-institutionalization, Maine's mental health program experienced a period of shifting strategies, contentious litigation, and heavy financial investment aimed at building a community mental health system.[21]

As it has built its community mental health system, DHHS has incorporated service components designed to support consumer involvement in their own recovery. For example, DHHS promotes individualized planning, driven by the individual goals; it funds peer support and recovery centers and plans to incorporate Certified Intentional Peer Support Specialist services into Assertive Community Treatment teams.[22] It is transitioning its

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[17] See 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, §17.02-3 Community Support Services for specific clinical eligibility criteria.

[18] Maine Department of Health and Human Services. November 2007. The Poor Health Status of Consumers of Mental Health Care: Prevalence, Quality of Care and Costs for Persons with SMI and Diabetes. Presentation by Commissioner Brenda Harvey, Elsie Freeman, and James Yoe at annual meeting of the American Public Health Association.

[19] Maine Department of Health and Human Services. Riverview Psychiatric Center, History of the Augusta Mental Health Institute. (http://www.maine.gov/dhhs/riverview/history/index.html. retrieved February 8, 2009.

[20] Maine Department of Health and Human Services. History of Dorothea Dix Psychiatric Center. http://www.maine.gov/dhhs/DDPC/history.shtml, retrieved November 24, 2008.

[21] Desisto, Michael. 1996. Adult Mental Health Services in Maine: Lessons from the Past; Hope for the Future. In Maine Choices 1997 – A Preview of State Budget Issues, Maine Center for Economic Policy.

[22] If its state plan amendment is approved by CMS. 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, §17.04-4.

residential services to a Supported Housing model, which is designed to provide flexible supports in integrated community housing; and it funds supported employment to help people find and maintain a job. Today, DHHS is using grant funding to focus on the integration of mental and physical health services, and the integration of substance abuse and mental health services.

Maine has developed three tiers of psychiatric hospitals, none of which are intended to provide long term services for their patients. Community hospitals provide psychiatric services and several have specialized psychiatric units. These hospitals serve people with short term acute care needs. Maine also has two regional specialty hospitals, Spring Harbor in South Portland and Acadia Hospital in Bangor. These two psychiatric hospitals serve people whose needs exceed the community hospital's capacity. Maine's state-operated facilities serve people with a longer term need for hospitalization. Maine does have three nursing facilities providing specialized services for adults with severe and persistent mental illness who also have physical health conditions that make them eligible for nursing care.

In 2007 DHHS introduced utilization review of its behavioral health system through an administrative service organization (ASO), aimed at making sure services are provided to those that need them, in the right amount and at the right time. DHHS is also pushing the local delivery system to increase coordination. DHHS has developed seven community service networks (CSNs) across the state, comprising providers and consumers in each service area. The CSNs are statutorily created and are responsible for developing an integrated system of care within each geographical area and ensure that core mental health services are delivered to consumers promptly and responsively.[23] Coordination across the mental health system is perceived to be a challenge – a lack of coordination across community providers and hospitals is perceived to be a cause of avoidable hospitalizations. Because of communication barriers between hospitals and community providers, risk avoidance, and other factors, hospitals often admit patients when a crisis might have been resolved in the community.[24] Similarly, when it's time for discharge planning, lack of agreement among the hospital and community providers can result in unnecessarily extended hospitalizations.[25] To begin to address the lack of coordination, DHHS recently charged each CSN with responsibility for collaboratively designing a crisis system in their service area, defining roles, the distribution of resources, and developing a proposed contract and memoranda of agreement.[26]

Maine's adult mental health system currently operates under a consent decree. To address deficiencies in one of Maine's state operated psychiatric hospitals as well as the lack of community services, a suit was filed in 1989, and a consent decree was ratified in 1990. In 2004, fourteen years after the consent decree was ratified, the court found that DHHS was far from being in compliance.[27] On review, Maine's Supreme Judicial Court ordered DHHS to develop a comprehensive plan for meeting the objectives of the consent decree.[28] DHHS' plan[29] was developed in 2006 and standards for achieving substantial compliance were approved in 2007.[30]

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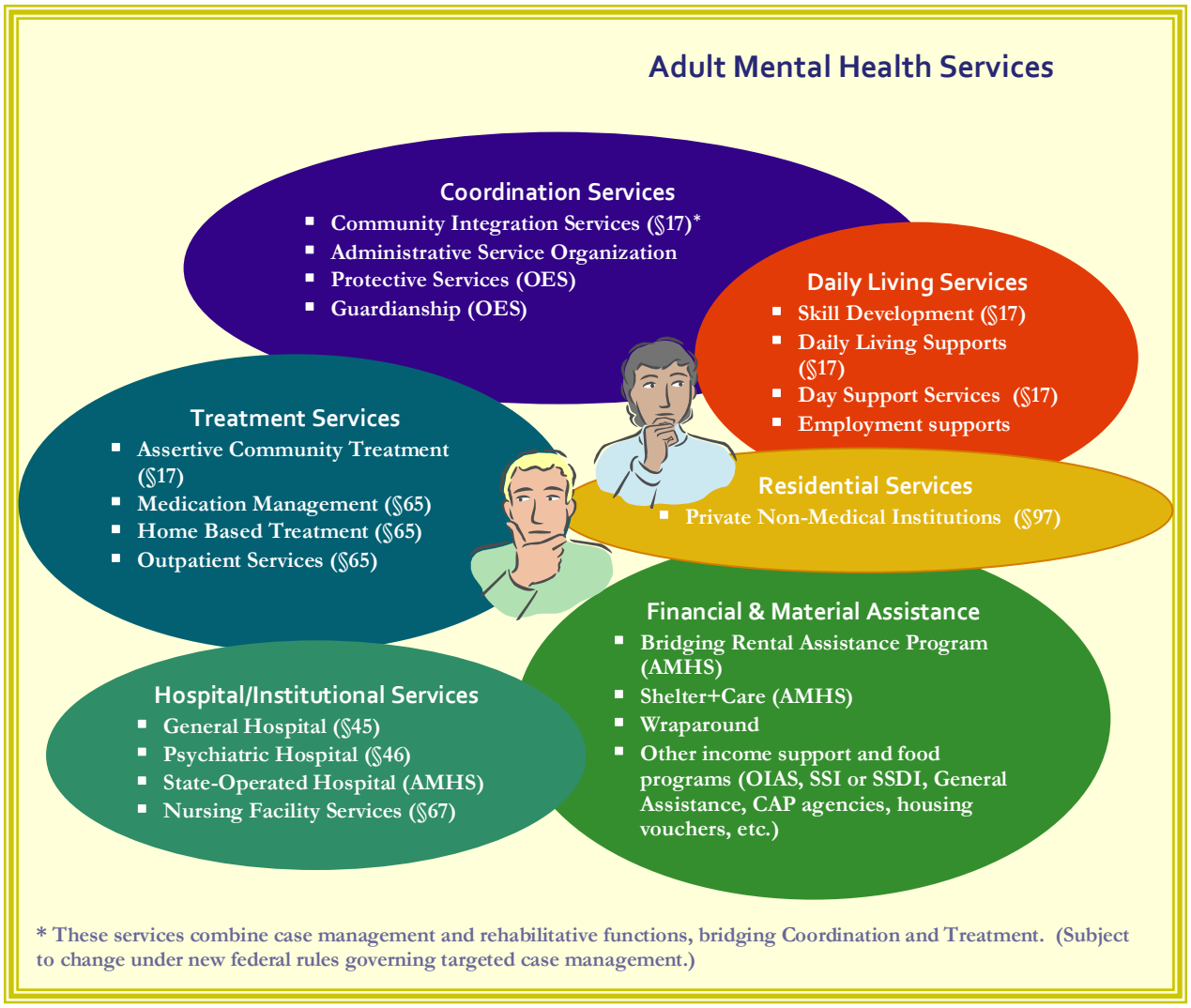
[23] Maine Department of Health and Human Services, Office of Adult Mental Health Services. January 15, 2008. Report to the 123 Legislature Joint Standing Committee for Health and Human Services.
[24] Stakeholder Meeting. May 23, 2008. Mapping Access to Mental Health Services for Maine's Systems Transformation Grant.
[25] Ibid.
[26] Chamberlain, Don. October 21, 2008. Memorandum to Providers of Mental Health Crisis Services and Hospitals.
[27] *Bates v. Duby,* No. 89-088 (Maine Superior Court, Kennebec County, May 23, 2004).
[28] *Bates v. Department of Behavioral and Developmental Services* (Maine Supreme Judicial Court 2004).
[29]Department of Health and Human Services Adult Mental Health Services Plan. October 13, 2006. Consent Decree Plan.
[30] *Bates v. Harvey*, No. 89-088 (Maine Superior Court, Kennebec County, Oct. 29, 2007).



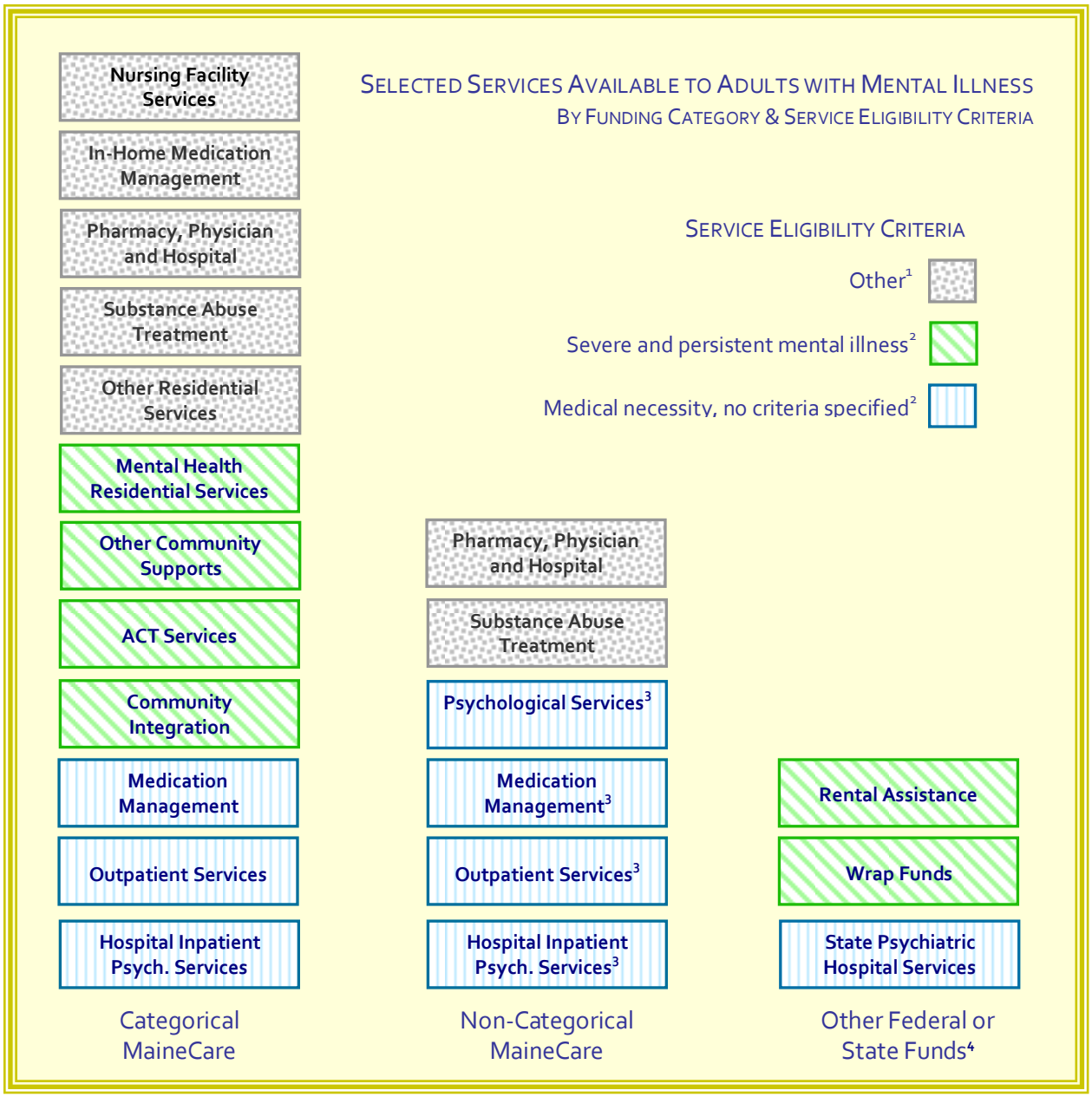
Services and Eligibility

DHHS provides an array of treatment and supportive services. Access to community and residential supports is primarily limited to persons with serious and persistent mental illness.[31] Three levels of benefits are available, depending on financial eligibility. Most adult mental health services are funded through MaineCare, which offers two levels of benefits depending on whether the individual satisfies certain eligibility criteria. People who are "categorically eligible," based on the presence of dependent children in the household or because of age or disability; have access to a more comprehensive benefit package. Adults who do not qualify as "categorically eligible" may be "non-categorically eligible" if they meet financial eligibility criteria. "Non-cats" can access coverage for some benefits. People may also be eligible for state-funded services. State-funded services can also supplement MaineCare services, when appropriate. The figure on page 45, SELECTED SERVICES AVAILABLE TO ADULTS WITH MENTAL ILLNESS BY FUNDING CATEGORY & SERVICE ELIGIBILITY CRITERIA, shows which services can be accessed based on clinical and financial criteria.

[31] DHHS has proposed a change to the functional criteria used to make this eligibility determination. The change is expected to reduce the number of people meeting the eligibility criteria, although DHHS anticipates that any cost saving will be shifted to serve this group in other ways. Access to treatment services is available based on medical necessity.

Adult Mental Health Services	Target Population	Funding Source
Coordination Services		
Community Integration Services. Community integration services combine service coordination function with a rehabilitative component.	Persons with severe & persistent mental illness	MaineCare §17
Daily Living Services		
Skill Development. Teaching based services that help an individual increase his or her independence by learning the skills necessary to access community resources, etc. *Daily Living Supports.* Personal supervision and therapeutic support to help a person develop and maintain the skills of daily living. *Day Support Services.* Agency-based training designed to the individual in the acquisition, retention or improvement of self-help, socialization, and adaptive skills.	Persons with severe & persistent mental illness	MaineCare §17
Employment Supports. DHHS uses state funds to pay for employment supports for people whose need for ongoing assistance to maintain a job exceeds the time-limited vocational rehabilitation services available through the Department of Labor.	Persons with severe & persistent mental illness	State funds
Treatment Services		
Outpatient Services. Professional assessment, counseling or therapeutic mental health services. *Medication Management.* Prescribing, administering and monitoring medications for treating and managing mental illness. *Home Based Treatment.* In-home mental health therapy or medication management for persons who are unable to travel to an outpatient setting because of a physical or mental health impairment.	Persons with mental illness	MaineCare §65
Assertive Community Treatment. ACT is an integrated service approach merging clinical, rehabilitative, and support services to people for whom other treatment approaches have been unsuccessful. ACT services are provided by a multidisciplinary team that must include a psychiatrist or nurse with advanced training in psychiatric mental health, a registered nurse, a certified rehabilitation counselor, a Certified Intentional Peer Support Specialist (CIPSS) (if approved in Maine's amendment to its Medicaid state plan), and a substance abuse counselor.	Persons with severe & persistent mental illness	MaineCare §17

Adult Mental Health Services	Target Population	Funding Source
Residential Services		
Residential Services. Residential services can be transitional recovery-focused services or long term residential services. They might provide minimal supports and little structure or an intensive level of supports and be highly structured. Residential services can be provided in a group setting or offered in individual apartments.	Adults with severe & persistent mental illness	MaineCare §97
Hospital & Institutional Services		
Hospital Services. Inpatient mental health services are provided through psychiatric hospitals or psychiatric units within a general hospital. Maine has two regional specialty hospitals, Spring Harbor in South Portland and Acadia Hospital in Bangor. In addition, DHHS operates two psychiatric hospitals, Riverview Psychiatric Center in Augusta and Dorothea Dix Psychiatric Center in Bangor. These hospitals provide adult forensic services and extended inpatient psychiatric treatment.	Adults with mental illness	MaineCare §45 & §46 State funds
Specialized Nursing Facility Services. DHHS funds three specialized community nursing facilities for people with mental illness. These specialized nursing facilities provide intensive, specialized services not available in other nursing facilities.	Adults with severe & persistent mental illness requiring NF level of care	MaineCare §67
Financial and Material Assistance		
Bridging Rental Assistance Program. The Bridging Rental Assistance Program provides a rental subsidy for up to 24 months or until the individual is awarded a federal housing subsidy, whichever is sooner. BRAP targets people who are leaving psychiatric hospitals, people who are homeless, and people moving to more independent living arrangements.	Adults with severe & persistent mental illness	State funds
Shelter+Care. Shelter+Care is a federal program funded by the U.S. Department of Housing and Urban Development to provide rental assistance and supportive housing services to people with disabilities who are homeless, including persons with chronic mental illness.	Adults with severe & persistent mental illness who are homeless	U.S. Dept. of Housing and Urban Development
Wrap Funds. DHHS uses Wrap Funds to meet needs that fall out of the mental health service package. For example, DHHS can use Wrap Funds to pay for the first month's rent, medications, dentures, getting a car fixed, etc.	Adults with severe & persistent mental illness	State funds



[1] MaineCare services not administered by the Office of Adult Mental Health Services. (*Note*: AMHS does provide additional funding to three specialized nursing facility with behavioral health units.)
[2] Services administered by the Office of Adult Mental Health Services.
[3] Count toward annual maximum of 16 outpatient visits per year.
[4] State-funded services are targeted toward persons with severe and persistent mental illness. Wrap funds can complement MaineCare services.

Roles in the Delivery System	
Roles	*Description*
Eligible Persons	Adults with mental illness, with particular focus on adults with severe and persistent mental illness.
I&R / Outreach / Referral Sources	People are referred to mental health services by a variety of sources, including self-referral, family members, primary care physicians, hospitals, crisis services, shelters, public safety or police officers, adult protective services, etc. Intensive Case Managers, state staff located in DHHS district offices conduct outreach, often in shelters and jails.
Case Manager	Case management is a component of Community Integration services, which is available only to persons with severe and persistent mental illness. Community Integration services also focus on rehabilitation. ACT services also include a case management component, but ACT services are primarily treatment and rehabilitative.
Service Providers	▪ Mental health agencies ▪ Community support providers ▪ Residential providers ▪ Individual practitioners ▪ Hospitals ▪ Specialized nursing facilities
Utilization Management	Community support services require prior authorization by an administrative service organization (ASO). The ASO does not review the initial provider determination of eligibility for other services, but does approved continued care for most mental health. Three regional mental health team leaders are responsible for authorizing admission to residential services. The housing coordinators match people with appropriate residential services based on certain department priorities (*e.g.*, people currently hospitalized in a psychiatric facility take priority over people currently living in the community).

The Delivery System

AMHS contracts with providers to provide mental health services. For almost all mental health services, access (eligibility determination and enrollment) is made through the individual provider. AMHS contracts with an administrative service organization (ASO) to provide prior authorization or continuing review for many of its services. AMHS itself plays several roles in the delivery system – AMHS provides outreach through its intensive case manager function, and it serves as the utilization manager for residential services. Community providers administer Wrap Funds.

Waiting Lists

DHHS does not have reliable information about waiting lists. Currently, providers say they have waiting lists for services; however DHHS is not able to confirm the accuracy or dimension of these reports, given the inconsistency in how providers manage waiting lists. DHHS also collects data on unmet need for services which also reflects shortages. However, DHHS is just beginning to work with this data and has questions about its accuracy.

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✕	Not Relevant to Population Group

Strategic Vision for a Balanced System

- **Vision statement**
  DHHS' vision for its mental health system is embedded in the Consent Decree and its accompanying Adult Mental Health Services Plan of 2006. In the Consent Decree, the parties identified guiding philosophies to underpin the mental health system: that the State needs to reallocate its significant investment in its state hospitals to develop a comprehensive mental health system as an alternative to hospitalization; that the mental health system was to recognize the dignity and individual needs of the persons served; and that treatment was to be provided in the least restrictive setting, as close to families and friends as possible.[32] These principles guide policy and budgeting decisions.

- **Monitors progress toward vision**
  DHHS has monitoring and reporting systems in place for measuring progress toward its vision and goals. For example, DHHS produces quarterly reports on its performance relative to consent decree requirements, on systems development, on performance and quality improvement, etc. As part of the process for completing this profile, DHHS has developed definitions that can be consistently used for its target population and services.

Consolidated State Agencies

- **Shifting resources**
  Under the Consent Decree, DHHS is required to provide shift resources from its state hospitals to its community based service system.

- **Coordinated policymaking**
  The Office of Adult Mental Health Services oversees all mental health services, including institutional, residential and community services. Policymaking, budgeting and other core management functions are centralized under the office director. AMHS needs to coordinate policymaking with the Office of MaineCare Services for Medicaid-funded services; with Purchased Services for contracted services; and with the Division of Licensing and Regulatory Services for quality assurance functions. AMHS is responsible for seeing that Consent Decree requirements are translated into policy and practice, and produces performance monitoring reports for the Court Master. DHHS' Integrated Management Team is a vehicle for coordinating policymaking for adult mental health services with other services and programs.

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[32] *Bates v. Glover*, No. 89-088, Settlement Agreement (Me. Super.Ct., Ken.Cty., August 2, 1990).

- Uses data to plan for services

  DHHS uses a variety of data sources to monitor service delivery and plan. For example, DHHS tracks hospital utilization by quarter, monitoring whether an individual has been hospitalized close to their home community (defined within the Consent Decree compliance standards). DHHS monitors the number of discharges from Riverview Psychiatric Center that are delayed by lack of residential options. DHHS also collects data on unmet need (although these data are not yet reliable), including unmet need for residential services. DHHS captures unmet need by collecting information about consumer resource needs that have not been met, as identified through the individualized support planning process. Although this data is not yet considered reliable, it has the potential to be an important tool for planning purposes.

Single Access Points

- Information and referral

  DHHS provides funding to support *211 Maine* as a general information and referral source. *211 Maine* is a statewide toll-free service for health and human services. It was built on an existing information and referral service for adult mental health services in southern Maine. *211 Maine* also offers an online searchable database with the ability to search information by region, including mental health services and housing services. Call data indicates that *211 Maine* is recognized as a source of information about mental health services – in FY 2008, 10% of calls were related to mental health services.[33] DHHS also funds NAMI-Maine, which provides specialized information and referral services for mental health services.

  There is inadequate information about whether or not these resources meet the needs of this population group. However, anecdotal information suggests that, because *211 Maine* began as a southern-Maine enterprise before expanding statewide, its visibility and comprehensiveness varies by region. In addition, maintenance of the information is based on voluntary updates by providers (with reminders).

- Linking with services

  For people able to access community integration services (that is, persons with severe and persistent mental illness), there is a systematic process for linking people to needed services and supports. It's the job of the community integration worker to make sure that the person is linked to needed services. However, for people who are not eligible for this level of service, there is no system resource available to help people identify and assess the service options that might be available to them.

- ✕ Coordinated community and institutional eligibility determination

  DHHS does not offer hospitalization as a long term setting for persons with mental illness. However, stakeholders have identified avoidable hospital admissions as a problem that needs to be addressed.[34]

  Maine has only three nursing facilities providing specialized services for persons with mental illness. Access to these services is through a single entry point for accessing institutional and home and community based services. See OLDER ADULTS AND ADULTS WITH DISABILITIES. For persons with mental illness, admission is reviewed by a mental health utilization review nurse.

- Coordinated clinical and financial eligibility

  The processes for determining clinical eligibility and MaineCare eligibility are conducted separately. A provider may refer an individual to apply for MaineCare but does not necessarily facilitate that process. Individual providers can confirm eligibility for MaineCare services, although this process can be cumbersome. Determining MaineCare eligibility can be challenging for this population group since eligibility is often based on a determination of a disability. The process can be delayed because there are problems in obtaining copies of medical records. Also, there is a perception that denials are more frequent when the

[33] Top 2-1-1 Call Categories FY 08, downloaded from http://www.211maine.org/call_reports.asp on March 12, 2009.
[34] See earlier discussion under PROGRAMS AND SERVICES.

claimed disability is a mental illness: because a mental health diagnosis is not always clear cut, a consumer might be denied eligibility if his or her medical records indicate a lack of clinical consensus.[35]

In the absence of a coordinated process, the process would be smoother if consumers had assistance in preparing a MaineCare application that involves documenting a disability.

- Person centered planning
  MaineCare rules define an individualized service plan as reflecting the strengths and needs of the individual; services that follow the individual's goal; and resources that will meet the needs of the individual's goals in the community, including the social supports available or in need of being created.[36] Certification as a community integration worker is competency based. One required competency includes knowledge about collaborative planning with people with psychiatric disabilities, including goal setting, skill assessment and training and linking with supports in the community.[37] Licensing standards for mental health services require that the service plan be designed so that progress toward goals can be monitored and evaluated.[38] Individualized planning is also a core value of the consent decree.

- Tracking waiting lists
  DHHS does have a system for tracking waiting lists and a system for monitoring unmet need. However, at this point in time, DHHS is not confident about the data being produced by either mechanism. DHHS asks providers to record those waiting for services in a centralized waiting list managed by the administrative service organization (ASO). Compliance with this request is still uneven. DHHS is also attempting to collect information on unmet need. However, issues with the data collection process and feeds into the data system mean that the data is not yet reliable.

  DHHS is currently working to improve the reliability of its waiting list and unmet need data.

Institutional Supply

- Privacy and autonomy considered
  Hospital licensing standards require psychiatric hospitals to ensure that the physical environment ensures privacy and require that patients be allowed to participate in planning recreational activities whenever possible. However, they do not address patient participation in meal planning and providing patients with flexible meal or activity schedules. All mental health services are governed by the Rights of Recipients of Mental Health Services, which sets standards for privacy and autonomy, including the right to space for private communications and the right to have personal property. These rights do not extend to the right to control one's own schedule, meals, and factors contributing to consumer privacy and autonomy.

- Controls on supply
  In 2004, Maine replaced its Augusta facility with a new facility, the Riverview Psychiatric Center, which is licensed to serve a maximum of 92.[39] Today, the Dorothea Dix Psychiatric Center serves a maximum of 100 people.[40] Increasing the number of licensed beds in Maine's psychiatric hospitals is subject to Maine's

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[35] Stakeholder Meeting, May 19, 2008, Mapping Access to Mental Health Services for Maine's Systems Transformation Grant.
[36] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 17.01-11.
[37] Maine Department of Health and Human Services, Office of Adult Mental Health Services. May 2008. Procedural Guidelines for Mental Health Rehabilitation Technician/Community (MHRT/C) Certification.
[38] 14-193 CMR Chapter 6, Mental Health Licensing Regulations, Section CS.8.
[39] Maine Department of Health and Human Services. Riverview Psychiatric Center, History of the Augusta Mental Health Institute. http://www.maine.gov/dhhs/riverview/history/index.html. retrieved February 8, 2009.
[40] Maine Department of Health and Human Servcies. Dorothea Dix Psychiatric Center. http://www.maine.gov/dhhs/DDPC/index.shtml, retrieved November 24, 2008.

Certificate of Need regulations.[41] Currently, DHHS has no plans to increase the number of public or private psychiatric hospital beds. DHHS does not offer incentives to reduce the supply of psychiatric hospital beds.

Nursing facilities are also subject to Certificate of Need regulations. (For more information on CON requirements for nursing facilities, see the INSTITUTIONAL SUPPLY discussion under OLDER ADULTS AND ADULTS WITH DISABILITIES, below.)

Transition from Institutions

- **Identifying people for transitioning**
  DHHS requires hospitals to have a preliminary discharge plan within three days of admission, with a full plan to follow seven days later.[42] DHHS monitors the length of time between the date a person is determined "ready for discharge" and the date of actual discharge. For example, in the reporting period of the 2009 fiscal year, 13, or 27%, of the delayed discharges were related to a lack of housing options.[43] For many, this delay is associated with highly specialized needs, often including medical needs.

- **Funds transition planning**
  A person who applies for community support services while an inpatient in a psychiatric facility must be assigned a community support worker within two working days. The community support worker participates in discharge planning and makes contact with the individual within three days of returning to the community. DHHS also facilitates the transition back to the community by coordinating access to residential services. First priority is given to people currently in state-operated psychiatric hospitals, second priority to those in specialty psychiatric hospitals, third priority to those in community hospitals.[44] Whenever possible, DHHS prefers to develop individualized residential supports for people transitioning out of state-operated psychiatric facilities, sometimes delaying the transition.

- **Funding for one-time transition expenses**
  Wrap Funds can be used for one-time expenses to facilitate transition, including first month's rent and other expenses associated with transitioning out of a hospital. In addition, DHHS has a Bridging Rental Assistance Program that provides rental assistance while people are on waiting lists for other public housing assistance. Again, persons transitioning out of a psychiatric hospital are given first priority for these funds.

A Continuum of Residential Options

- **Privacy and autonomy considered**
  Currently, mental health residential services are dually licensed under licensing regulations for mental health agencies and the Assisted Housing licensing regulations. Assisted Housing licensing regulations articulate an individual's right to privacy and the right to choose his or her activities. The regulations require residential providers to solicit residents' preferences when planning activities and to encourage residents to participate in meal planning and to use their own furnishings in their rooms. The licensing regulations however do not place a heavy emphasis on privacy and control and do not require staff to be trained in person centered care or services. DHHS is currently revising its licensing regulations for residential mental health services. However, all mental health services are governed by the Rights of Recipients of Mental Health Services, which sets standards for privacy and autonomy, including the right to the least restrictive environment, the right to space for private communications, and the right to have personal property. These rights do not

[41] 10-144 CMR Chapter 503, Maine Certificate of Need Procedures Manual, Chapter 4(1)(B)(5).
[42] 14-193 CMR Chapter 1, Rights of Recipients of Mental Health Services, Part B(III)(E).
[43] Maine Department of Health and Human Services, Adult Mental Health Services. October 2008. Performance and Quality Improvement Standards, Standard 14 Measure Method 6.
[44] Stakeholder Meeting. May 23, 2008. Mapping Access to Mental Health Services for Maine's Systems Transformation Grant.

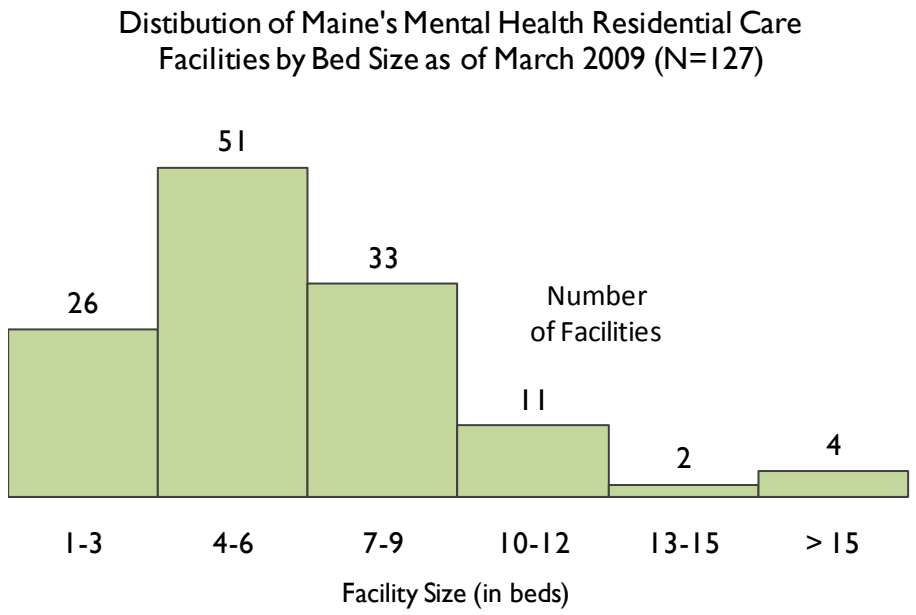
extend to the right to control one's own schedule, meals, and factors contributing to consumer privacy and autonomy.

- Range of options.
  DHHS provides a range of options to serve people across a range of settings including rental assistance, daily living services, supportive housing, and group homes.

  Supportive Housing. Supportive housing are daily living services provided in an individual's home or apartment, or other living arrangement according to individual need. Supportive housing services are not tied to a particular residential setting. Daily living services include personal supervision and therapeutic support to develop and maintain daily living skills and to retain community tenure.[45] Services may include housekeeping or home maintenance, meal planning and preparation; transportation; interpersonal relationships, self advocacy and assertiveness training; health maintenance and safety practices; financial, personal and legal affairs management, contingency planning and decision making; basic academic, work and recreational skills; and utilization of community services and resources.[46]

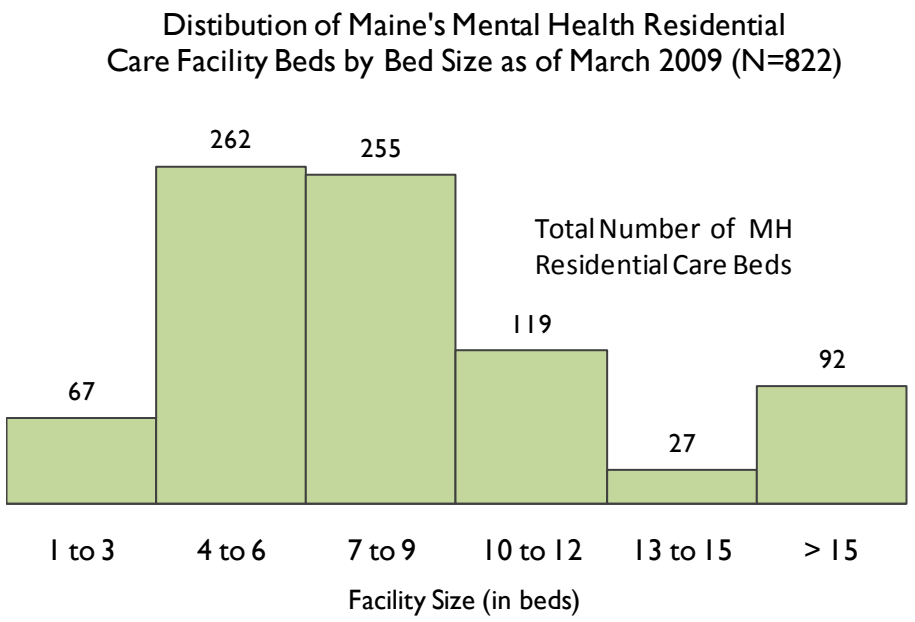
  Residential Services. Residential services link housing and mental health services and include both long term residential services or transitional, recovery focused programs. The residential and program services include: providing or arranging for comprehensive treatment to include: medical, psychiatric, and other specialized services, training and support; transportation; and development of life skills. The services can be provided in a large group setting or in "scattered site" apartments.

The chart below shows the number of residential services by size. The chart on the next page shows the number of beds available by size of setting.



Source: APS Healthcare, "Adult Mental Health PNMI Bed Occupancy Daily Report" (Excel Spreadsheet posted on the world wide web at: http://www.qualitycareforme.com/Maine_Adult_MH_Facilities.htm, accessed on March 12, 2009.

[45] Ibid, §17.04-5.
[46] Sheldon Wheeler, Cindy Namer, and Holly Stover, Housing Work Group Overview (Draft), Maine Systems Transformation Grant, (Undated).



Source: APS Healthcare, "Adult Mental Health PNMI Bed Occupancy Daily Report" (Excel Spreadsheet posted on the world wide web at: http://www.qualitycareforme.com/Maine_Adult_MH_Facilities.htm, accessed on March 12, 2009.

- Up-to-date information about available options

  Consumers and providers do not have readily available information about affordable, accessible housing options. However, DHHS is working with its partner, Maine State Housing Authority, to build a housing registry. When fully implemented, the housing registry will provide a searchable database of both DHHS and MSHA supported housing options. DHHS expects the registry to be publicly available by the summer of this year. In the meantime, DHHS has contracted with its Administrative Service Organization to produce a daily report on bed occupancy for residential facilities. This report is accessible to providers and the general public on the ASO's website.[47]

  DHHS and MSHA are moving forward to make the housing registry operational; DHHS needs to ensure that its residential options are included in the registry, along with the subsidized housing options available through MSHA.

Long Term Services and Supports Infrastructure Development

- Case management

  Case management is a component of Community Integration services provided to persons with severe and persistent mental illness. The Community Integration worker facilitates access to an array of long term supports and services.

- Develops workforce to meet needs

  DHHS supports a comprehensive training and certification program from multiple levels of mental health rehabilitation technicians (MHRTs). The MHRT-1 provides direct support services and completes a competency based training curriculum to obtain certification. Helping an individual to be part of the community is defined as the overarching purpose of the direct support role. The MHRT/Community level

[47] APS Healthcare. Adult Mental Health PNMI Bed Occupancy Information. (http://www.qualitycareforme.com/Maine_Adult_MH_Facilities.htm) retrieved

of certification is for the community integration worker, which provides case management and rehabilitative services. Recent enhancements to that curriculum include a new required module focusing on the vocational aspects of disability, to promote employment. DHHS has recently added a new certification for MHRT/Crisis workers. DHHS monitors unmet need for daily living and skill development services; the data on unmet need shows shortages of these services, although DHHS is not satisfied with the accuracy of this data. DHHS monitors the adequacy of caseloads for community integration workers.

- Support for informal caregivers

DHHS reports that it currently does not have data on the need for caregiver supports for this population group. It does fund some respite services for family members (a total of $48,272 in FY08), as well as support groups.

- Uses evidence based practices

DHHS has developed an Evidence Based Practice (EBP) coordinating committee to promote the statewide development and implementation of evidence based and promising practices. It has also articulated its vision and principles to guide implementation of evidence based adult mental health practices in Maine; it promotes the use of evidence based practices by making resources available on its website.[48]

Evidence Based Practice	Implemented
Assertive Community Treatment	Most of state
Supported Employment	Statewide
Family Psychoeducation	Part of state
Integrated Mental Health & Substance Abuse Services	Part of state
Supported Housing	Statewide

DHHS has implemented several evidence based practices, including supported employment; Assertive Community Treatment which has been shown to reduce psychiatric hospitalization, increase housing stability and improve quality of life for persons experiencing severe and persistent mental illness;[49] supported housing; and, through a Co-Occurring State Incentive Grant from the Substance Abuse and Mental Health Services Administration, Maine is also in the process of implementing integrated treatment for people with dual diagnoses of mental illness and substance abuse addiction. Not all evidence based practices are implemented statewide; in some cases demand for services is not sufficient to support the service.

- Stakeholders participate in planning for services

In 2008, DHHS established a statewide system of consumer councils to participate in quality assurance activities and make recommendations for systems change. The consumer councils participate in the assessment of the quality, accessibility, and adequacy of services within their regions. The Consumer Council System of Maine is funded by AMHS.[50] In addition, consumers participate on the Community Service Networks (CSNs) that are responsible for fostering coordination within the local service delivery system.

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[48] Maine Department of Health and Human Services, Office of Adult Mental Health Services. Evidence-Based Practices (EBP) Resources. http://www.maine.gov/dhhs/mh/evidence-based_practices.html accessed March 13, 2009.

[49] Yoe, James T. and Karen Glew. 2008. Assertive Community Treatment in Maine: Evaluating Fidelity, Service Use and Outcomes. Maine Department of Health and Human Services, Office of Quality Improvement. In this report, Maine's Office of Quality Improvement evaluates how well Maine has implemented the ACT model.

[50] Consumer Council System of Maine. http://www.transformationinme.org/welcome.html accessed March 13, 2009.

Consumer Direction

- ○ Individualized budget
  DHHS' ability to offer a consumer directed option is limited by the fact that it does not currently have the tools in place for developing an individualized budget for each individualized service plan. Services are arranged by provider contract, with funding attached to the provider rather than the individual being served.

- ○ Option to hire own workers
  DHHS does not offer consumers the option to hire their own workers.

- ○ Option to purchase goods and services
  Consumers do not have discretion to purchase goods and services outside the standard service package.

Quality Management

- ◉ Quality management plan
  DHHS has a quality management plan for adult mental health services, although it is not fully implemented. The plan designates the Director of the Office of Adult Mental Health Services and the senior management of the office as responsible for the overall effectiveness of the quality management system. The OAMHS Director of Policy is charged with carrying out day to day responsibility for the implementation and management of the quality management system. The OAMHS Quality Management Plan will be updated at least annually by the OAMHS Director of Policy and reviewed and approved the Senior Management Team of the Office.

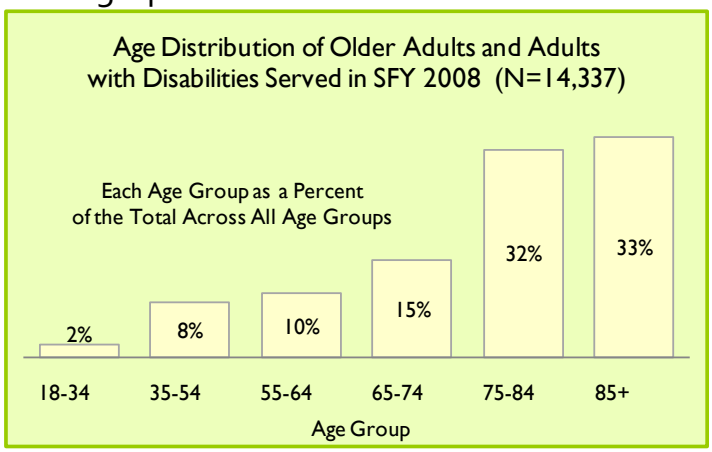
- ◉ Quality measurement
  OAMHS collects a lot of data and does use it for decision making. However, the system is still evolving. Data elements and their sources have been identified and documented in OAMHS' quality management plan. The Quality Management Reports grid specifies reporting frequency and recipients of the various quality reports.

- ● Consumer surveys
  DHHS conducts a Class Member Survey annually with results provided to OAMHS, the Consumer Council and posted on DHHS' website. In addition, DHHS conducts a data infrastructure grant survey. Both of these surveys look at satisfaction, perception of care, functional outcomes, etc.

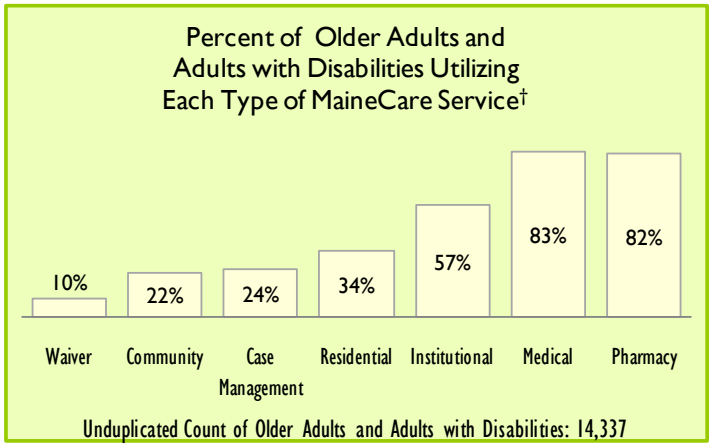
Older Adults & Adults with Disabilities

Older Adults and Adults with Disabilities

Demographics



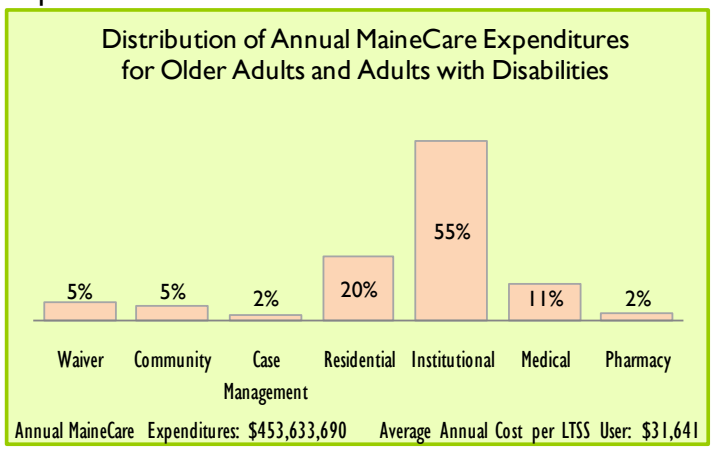
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- 57% of this group accessed institutional services (*i.e.* primarily nursing home services) 34% accessed residential care services.
- 10% have accessed in-home waiver services while 22% have received community services which include MaineCare state plan in-home services.
- Of the 14,337 members identified in this group, 1,645, or 11%, are also in one or more other adult groups. The biggest overlap (965) is with those identified in the adults with mental illness group.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- Nursing facility services and residential services, at 55% and 20% respectively, are the major cost drivers for this group.
- Waiver expenditures only represent 5% of total costs.
- Other medical costs represent 11% of the total costs for the group. Almost half of the medical costs are for inpatient services.
- Analysis of those who are eligible for both MaineCare and Medicare will provide further insight into these cost components.

System Strengths

Integrated Access. DHHS uses a uniform assessment process to integrate access to a range of services including home and community based services funded under MaineCare state plan, two MaineCare waivers, and state-funded programs.

Diversion. DHHS has built diversion into its single entry point system, providing consumers an option to be considered for nursing facility or home and community based services through one process. DHHS would like to examine the effectiveness of its diversion efforts.

Rate Setting. DHHS uses assessment data to inform rate setting for services.

Evidence Based Practices. DHHS has leveraged grant funding to implement evidence-based practices.

State-Funded Services. DHHS offers an array of state-funded services to complement those available through MaineCare. These services provide low cost home care that help to reduce the need for a higher level of service.

Areas for Further Examination

Information and Referral. Maine is working toward offering consistent statewide access to general and specialized information and referral. Currently there is uneven access to low barrier assistance for evaluating a comprehensive array of long term support options.

Person Centered Planning. DHHS has expressed interest in strengthening person centered planning as an expectation for its providers.

Facility Size. DHHS would like to explore strategies for reducing the number of large nursing and residential care facilities.

Aging Population. As Maine's population ages, DHHS will need to evaluate its readiness to serve an increasing number of older adults.

DEFINITIONS AND DATA

Older adults and adults with disabilities include members residing in nursing homes, residential care settings, or in housing with assisted living services; members receiving waiver services for older adults and adults with disabilities, private duty nursing, or day health services.

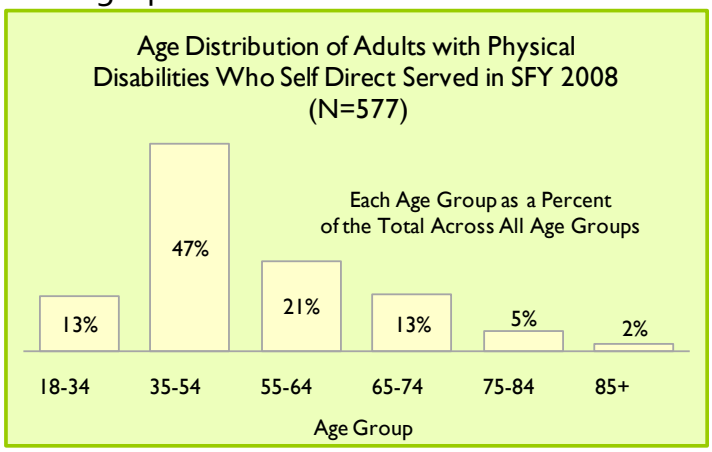
> NOTE: Those adults with physical disabilities who are on the consumer directed waiver or receiving consumer directed services under the state plan are analyzed separately on the next page.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. Adult members may be in more than one office population; therefore, adult office populations should not be added. Adult totals shown here have been aggregated as distinct counts and dollars.

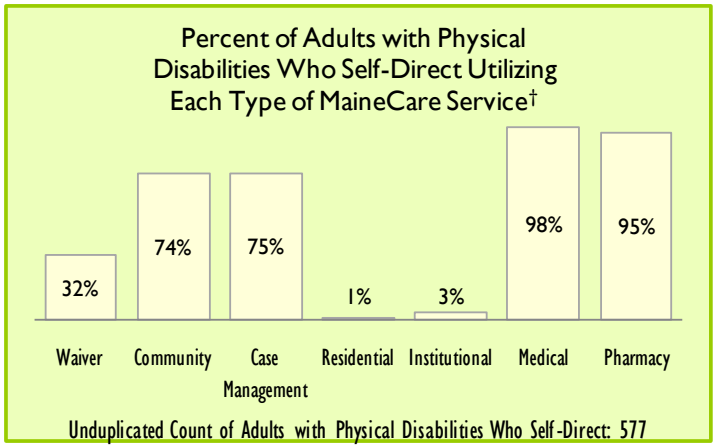
See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

Adults with Physical Disabilities who Self-Direct

Demographics



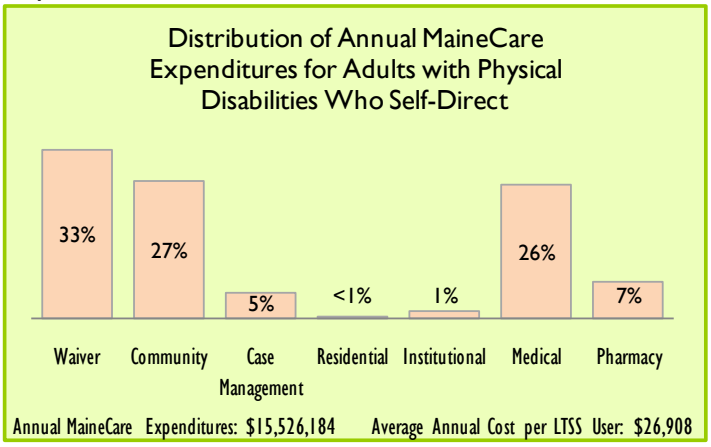
Utilization



†The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- 32% of the people in this group accessed waiver services.
- 74% accessed MaineCare state plan consumer directed services.
- 98% of the members in this group accessed medical services and 95% accessed pharmacy services.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- Waiver service costs and other community costs represent the major cost components.
- Medical costs represent approximately one quarter of the MaineCare expenditures for this group. The major costs in this category are inpatient and outpatient hospital costs, durable medical equipment, and medical transportation.

System Strengths

Strong Focus on Independence & Consumer Control. Maine's consumer directed programs have been a national model since the first was created in the late 1970s. They have a strong focus on independence and consumer control over decision making, including who provides the services and how they are provided.

Areas for Further Examination

Building Infrastructure. The consumer-directed programs have finally settled in a home after several years of bouncing from program office to program office. In its new home, DHHS is still building the infrastructure to support these programs. Areas still under development include strategies for stakeholder engagement and quality management.

Expanding Access. Access to these consumer directed services is limited to those who have the cognitive capacity to self-direct; there are models of supported or surrogate decision making that allow access to consumer direction for those with a cognitive disability.

DEFINITIONS AND DATA

Adults with physical disabilities who self-direct are members who are receiving consumer directed waiver or consumer directed state plan services.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. Adult members may be in more than one office population; therefore, adult office populations should not be added. Adult totals shown here have been aggregated as distinct counts and dollars.

See PROCESS AND APPROACH for more detail on how service categories are defined.

Older Adults and Adults with Disabilities

DHHS serves older adults and adults with disabilities. At its most basic level, this group is defined by a long term need for nursing or other medical care, or a need for assistance with activities of daily living. Because this population group is defined by a functional need for services rather than a diagnosis, the cause of disability can include a congenital or acquired physical disability, a chronic illness, dementia, or a variety of other conditions contributing to a physical or functional limitation. The range of disabilities experienced in this population group includes physical, sensory, cognitive and behavioral; in addition, the type and acuity of medical needs can vary widely.

Often older adults have only acquired their disability with age and have otherwise shaped their lives without reference to disability or impairment. For other adults that have acquired their disability at a younger age, their disability may play more of a role in shaping the opportunities available to them over their lifetime. Although the starting point might be different, people in both groups often share similar goals – maintaining their independence and their place among family and friends.

Programs and Services

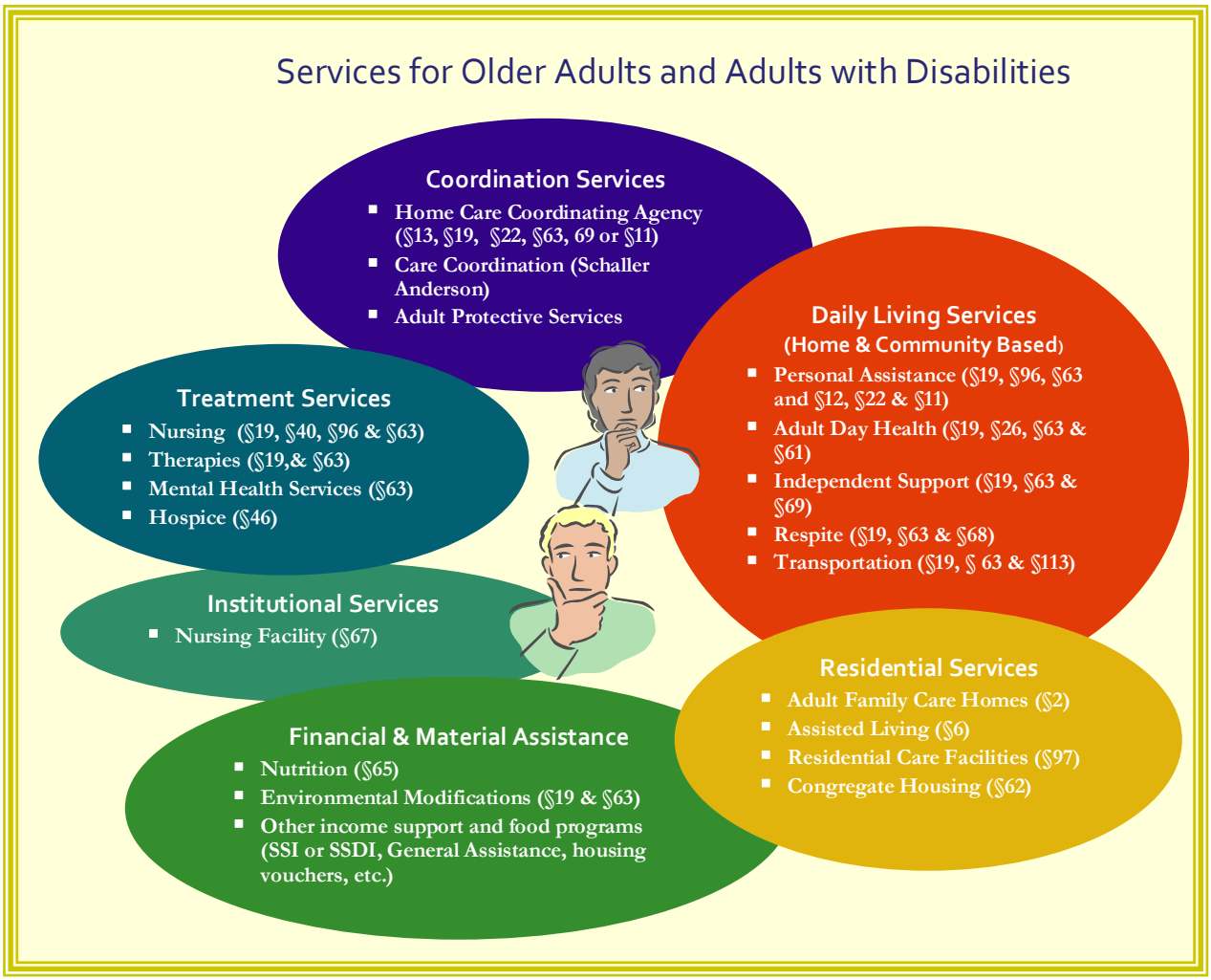
In 1979, Maine became one of the first in the country to develop a consumer directed program for persons with physical disabilities. Following in 1986, Maine developed both a consumer directed waiver program as well as a waiver program with a wider array of services for older adults and adults with disabilities. However, it wasn't until a budget crisis in the mid-nineties that Maine instituted a series of reforms aimed at limiting access to nursing facility services and redirecting resources to home and community based services. Medical eligibility standards for Medicaid-funded nursing home care were tightened so that nursing care funds would be directed toward persons with the greatest medical need. To ensure that people spend their long term care dollars as cost-efficiently as possible, legislation was enacted requiring anyone seeking nursing facility care to be assessed for medical need. Between 1994 and 2000, the number of MaineCare members in nursing homes, on average in a month, dropped almost 30% while the number of people receiving HCBS waiver services increased 50%. These trends continued from 2000 to 2006. During this time, the number of MaineCare nursing home residents declined 13%; the number of residents in residential care facilities increased 28% and the number of people using personal care services increased 88%.[51] DHHS continues to focus most of its efforts on nursing facility diversion, rather than transition.

Services

DHHS divides its home based services across two primary delivery models. The largest delivery model is managed by a statewide home care coordinating agency which is responsible for helping consumers implement an array of home care services. A family provider service option is available under this model, for people that want to direct their own care. The second model is a consumer directed personal assistance targeted at persons with physical disabilities (*i.e.*, persons having the cognitive capacity to direct their own care). In this model, the service coordination function focuses primarily on supporting consumers in the selection and payment of their employees. Both models are available as a MaineCare state plan benefit, MaineCare waiver, or as a state-funded service.

These two models are administered by two different offices within DHHS. The Office of Elder Services plays the primary role, while the Office of Adults with Cognitive and Physical Disabilities has a developing role. OES

[51] Fralich, Julie. 2008. Historical and Projected Use of Long Term Care Services in Maine. Presentation to Blue Ribbon Commission on Home and Community-Based Care. Muskie School of Public Service, University of Southern Maine.



also administers assisted living, adult family care homes, independent housing with services, adult foster care homes, and residential care facility services. Medicaid funded nursing facility services are available to persons who meet medical eligibility criteria. See the table on the next page for an outline of the difference between these models and the other services administered by these two offices.

Through Maine's five area agencies on aging, several other services are available including information and referral, nutrition (home delivered meals and community dining sites), and respite for caregivers for persons with Alzheimer's. The area agencies also provided family caregiver support and health insurance counseling

Some services are capped at different levels depending on individual need, or other program requirements. Service caps and co-pays are shown on page 64.

Eligibility

Eligibility for most elder and adult services is tied to the need for assistance with activities of daily living (ADLs), including eating, bathing, dressing, mobility, locomotion, etc.; instrumental activities of daily living (IADLs), including laundry, meal preparation, grocery shopping, and housework; and nursing services and other skilled medical services, including tracheostomy care, dressings, injections, intravenous feedings, administration of oxygen, insertion and maintenance of catheters, therapies, management of cognitive behaviors and symptoms,

etc. The picture on page 65, SELECTED SERVICES AVAILABLE TO OLDER ADULTS AND ADULTS WITH DISABILITIES, shows which services are available depending on the funding category and clinical eligibility.

MAJOR ELDER AND ADULT PROGRAMS ADMINISTERED BY OES & OACPDS

	OES			OACPDS		
	MaineCare State Plan	MaineCare Waiver	State Funded	MaineCare State Plan	MaineCare Waiver	State Funded
Age Group						
• 18+	√	√	√	√	√	√
Scope of Services						
Agency-Based Personal Assistance	√	√	√			
Family Provider Service Options Personal Assistance	√	√	√			
Respite		√	√			
Consumer Directed Personal Assistance				√	√	√
Nursing Services	√	√	√			
Independent Support Services		√	√			
Adult Day Services	√	√	√			
Residential Services	√		√			
Nursing Facility	√					

The Delivery System

Most elder and adult services are accessed through Maine's Single Entry Point, an independent Assessing Service Agency, for determining medical eligibility for service. Once program eligibility is determined, an individual choosing home care is referred to the appropriate service coordinating agency. See the side-by-side below for a representation of the differences and similarities across the OES and OACDPDS programs. People accessing nursing facility and residential services identify their provider without assistance from a case manager.

The local Area Agencies on Aging (AAAs) also play a supportive role in accessing long term support services, by providing information and referral services. Some AAAs help consumers prepare their Medicaid applications. Some AAAs and ADRCs offer case management services for a fee, depending on the region.

ENTRY POINTS AND COORDINATION SERVICES FOR HOME & COMMUNITY BASED SERVICES

	OES Administered Home-Based Services			OACPDS' Administered Personal Assistance		
	MaineCare State Plan	MaineCare Waiver	State Funded	MaineCare State Plan	MaineCare Waiver	State Funded
Entry Point	Assessing Service Agency					
Coordination	Statewide home care coordinating agency implements home service plan.			Service coordinating agency supports consumer in selecting and managing personal assistant services; provides fiscal intermediary services.		
In-Home Providers	Primarily home care agencies			Personal assistants		

Roles in the Delivery System	
Roles	*Description*
Eligible Persons	Persons needing assistance with activities of daily living, instrumental activities of daily living or nursing services. People seeking older adult and adult services might include: • People with an acquired need for services either because of injury, illness or aging. • Young adults with a disability transitioning to adult services.
I&R / Outreach / Referral Sources	Area Agencies on Aging/Aging and Disability Resource Centers, physicians, hospitals, family caregivers, self-referrals, OIAS eligibility workers, community service providers, advocacy agencies, Office of Child and Family Services, nursing facilities, residential facilities, care managers (any system), legal services, lawyers, protective services, advocacy associations, etc.
Case Manager	Case management services are provided by one of three service coordinating agencies, depending on whether a person is accessing home care services, consumer directed personal assistance or independent support services. The function of each depends on which type of service is accessed. Case management services are not available unless a person is accessing home and community based services.
Service Providers	The type of service provider will depend on which program a person accesses. Providers will include nursing facilities and residential providers. In addition, the HCCA will contract with or facilitate access to the type of in-home service provider connected to the program they administer: home health agencies, personal assistants, and homemaker agencies.
Access Management	The Assessing Services Agency (ASA) serves as the utilization manager for in-home and nursing facility services. The ASA assesses medical need for services; determines eligibility, and develops an authorized service plan. No utilization manager controls access to residential services.

Waiting Lists

DHHS currently has several waiting lists although it does not consider all of its waiting list information to be accurate. There is some indication that wait lists for these programs is eroding the state's ability to divert people from nursing facilities – a significant number of people are removed from the state-funded home based care wait list because they are entering a nursing facility.[52] Information on people waiting to access residential care or nursing facility services is not maintained on a statewide basis.

Waiting Lists for Elder & Adult Services (March 2009)	
Program	Count
Consumer-directed MaineCare waiver	101
State-funded consumer-directed personal assistance	9
State-funded home based care	26
State-funded independent support services	1070
State-funded adult day care	5
Respite services (Alzheimer's program)	28
State-funded assessments	120

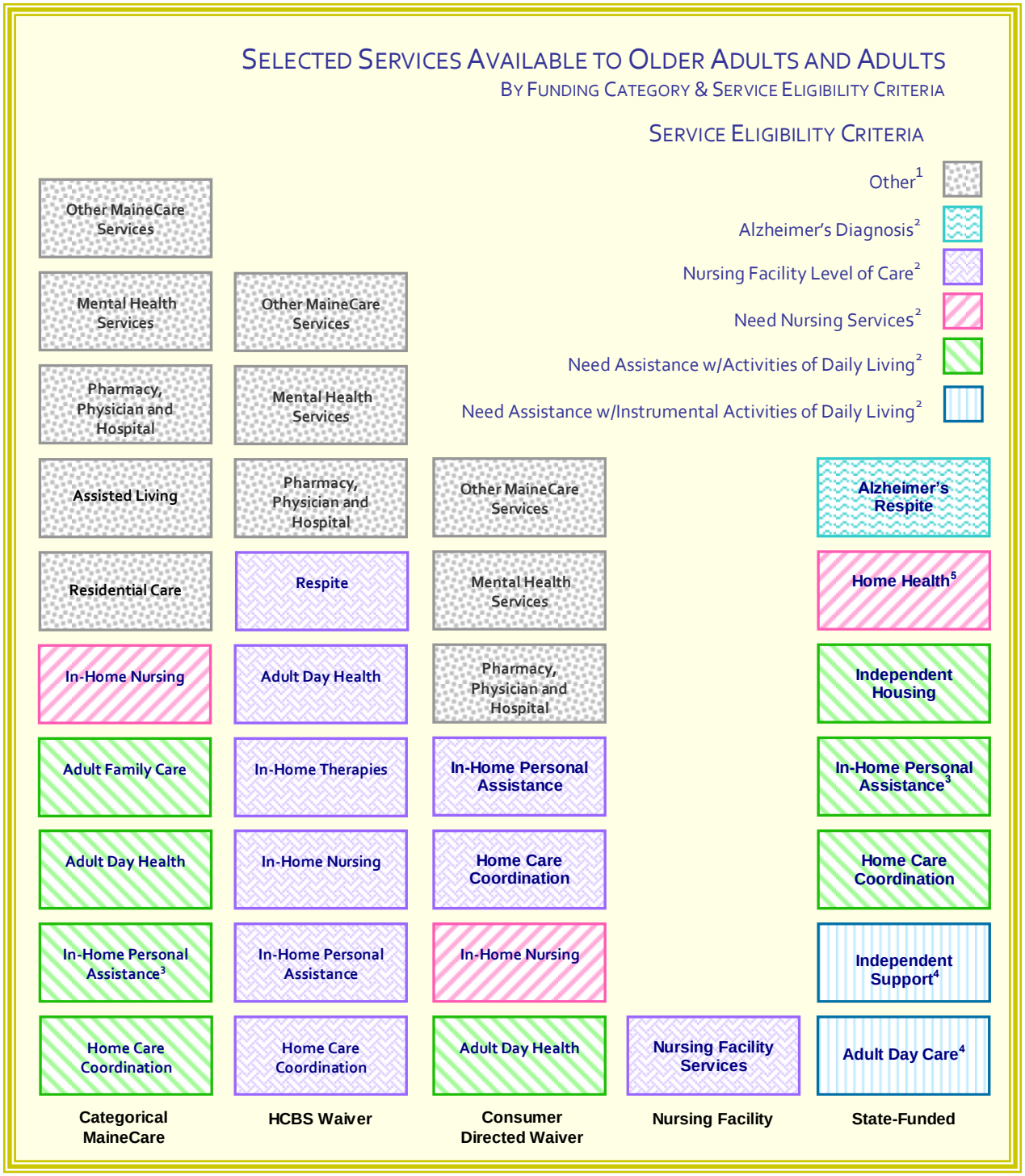
[52] Maine Department of Health and Human Services, Office of Elder Services. February 25, 2009. Home Based Care Wait List Statistics.

Limits on Services and Co-Pays

MaineCare State Plan	
Service Caps	**Co-Pays**
Private Duty Nursing/ Personal Care Services	$5/mon
I: $750/mon II: $950/mon III: $1,150/mon V: $20,682/mon VI: $2,400/mon VII: $12,000/mon VIII: $750/mon	
Adult Day Health	
I: 16 hr/week II: 24 hr/week III: 40 hr/week	
Consumer Directed Personal Assistance	
I: $474/mon II: $710/mon III: $1,105/mon	
Residential Services	Depends on monthly income. Generally residents keep up to $70/mon
Difference between net monthly income & MaineCare reimbursement	
Adult Family Care Homes	
Based on needs of resident	

Waiver Services	
Service Caps	**Co-Pays**
Elder/Adult Waiver	Countable income > 125% of poverty
100% NF ($4,341/mon)	
Consumer Directed Waiver	
100% NF aggregate; limit of 86 hr/week	

State Funded Services	
Service Caps	**Co-Pays**
Home Based Care	4% of monthly income + 3% of assets > $30,000
I: $900/mon II: $1,100/mon III: $1,675/mon V: $20,682/mon VI: 80% NF (3,473/mon)	
Consumer Directed Personal Assistance	
Up to 30 hr/week plus nighttime hours < 10 hr/ week for specific ADLs	
Independent Support	20% of cost of services
6 hr/mon	
Adult Day	
Attend min. of 4 hr/week	
Respite	
Max. of $3,500/year	
Independent Housing	
Based on needs of consumer	



[1] MaineCare services not administered by OES or OACPDS.
[2] Services administered by OES or OACPDS. (Note: OES and OACPDS do not administer residential services but OES does inform policy development for these services.)
[3] Includes both agency-based and consumer directed personal assistance.
[4] People who are financially eligible for MaineCare may access these services if they are not medically eligible for MaineCare funded in-home personal assistance or adult day health services.
[5] Available only to those accessing personal assistance through agency-based home care services (OES §63), not consumer directed personal assistance (OACPDS §11).

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✕	Not Relevant to Population Group

Strategic Vision for a Balanced System

● Vision statement

The authorizing statute for the Office of Elder Service articulates a commitment to efficient community services; freedom, independence and the free exercise of individual initiative, suitable housing and a range of other objectives.[53] OES has also articulated three strategic priorities for its long term services and supports:

◉ Monitors progress toward vision

In 2007, OES commissioned a study of actual and projected utilization and expenditures for long term services and supports.[54] OES sees this baseline report and projections and the information contained in the State Profile as a foundation for operationalizing its vision by setting goals for an appropriate balance of services and aligning budgets and policy to achieve those goals. From the baseline report, OES uses the distribution of people across settings as a tool for assessing its progress. As part of the process for developing this profile, DHHS has developed agreed upon definitions for population groups, services and units of service.

OES' Strategic Priorities

- People live and have responsibilities in their communities.
- People experience continuity and security.
- Services build on strengths and respond to needs of individuals.

Consolidated State Agency

○ Shifting resources

DHHS does not have the flexibility to shift funds across institutional and community services within a budget cycle. In its final report, the Blue Ribbon Commission to Study the Future of Home-based and Community-based Care recommended that the Legislature develop "a unified budget for long term care to facilitate coordinated planning and to allow the transfer of funds among programs to ensure that programs are serving individuals in their preferred settings."[55] Legislative authority is required in order for DHHS to have the needed budget authority.

[53] 22 MRSA §5103.

[54] The Lewin Group and the Muskie School of Public Service. 2008. *Projections of State and County Level Long Term Care Need and Use in Maine, 2006-2015*.

[55] Blue Ribbon Commission to Study the Future of Home-based and Community-based Care. November 5, 2008. Final Report.

- Coordinated policymaking

  In recent years, management of elder and adult services has become less integrated. Prior to 2002, a single state agency, the Bureau of Elder and Adult Services (BEAS, the predecessor for today's OES) was responsible for managing all older adult and adult services, including the consumer directed programs. During the 2002 legislative session, the administration of the consumer directed personal assistance services was moved out of DHHS and over to the Bureau of Rehabilitation Services, within the Department of Labor. Today, all three consumer-directed programs are administered by OACPDS while the Office of Elder Services continues to set policy for programs that serve both older adults and adults with disabilities. See the grid, SIDE-BY-SIDE: ELDER AND ADULT PROGRAMS ADMINISTERED BY OES & OACPDS, for a comparison of the populations and services served by the programs administered by these two offices. DHHS reports that coordinating policymaking across these two offices has not created problems.

  OES is responsible for managing a wide array of home and community based services, developing residential resources including assisted living and adult family care homes, and administering funds for adult day programs. OES is also responsible for overseeing the local area agencies on aging programs, the long term care ombudsman program, and the legal services program. At one time OES was also responsible for issuing CONs for nursing facilities and licensing assisted living and residential care facilities. Following DHHS' reorganization in 2004, these functions were brought in under the Division of Licensing and Regulatory Services. OES works with the Office of MaineCare Services to set policy for nursing facility services. The Integrated Management Team serves as a vehicle for coordinating policymaking across these different offices of DHHS.

- Uses data to plan for services

  DHHS' 2007 study of actual and projected utilization and expenditures for long term services and supports examines historical use of long term services and develops a model for projecting future use of services using varying assumptions. The model projects population growth by age group and estimates the future use of services in each age group. DHHS can vary the assumptions related to nursing home use rates, inflation rates, and rates of disability in the general population. DHHS is using the model for planning and for discussion with its stakeholder groups. The model can be used to identify areas of over or under supply of nursing or residential care beds by county.[56] The projection model for long term services is being updated in 2009 to include estimates of the number of residential care beds needed in the future. The baseline model is also being used to plan for home care services.

Single Access Points

- Information and referral

  Maine has five area agencies for aging (AAAs) which are visible sources of information and referrals for older adults. Under Maine's Aging and Disability Resource Center (ADRC) grant, three of Maine's AAAs developed additional capacity to serve as the primary source of information about long term services and supports for all adult population groups. DHHS has not established statewide standards for the ADRCs and currently does not fund the higher level of service expected from an ADRC, although all three express a commitment to continuing to serve in that capacity. Maine's 211 system offers a resource database. However, Maine's three ADRCs found *211 Maine* alone to be not sufficiently specialized to meet the needs of older adults and adults with disabilities. Important next steps would include defining standards for the ADRCs, expanding (and funding) their reach statewide, and ensuring the availability of a resource database for this population.

[56] The Lewin Group and the Muskie School of Public Service. 2008.

- Linking with services

  Maine's five area agencies on aging (AAAs) provide entry to a comprehensive array of long term services and supports for older adults. However, the AAAs do not have uniform standards for providing this service. In addition, except for the three AAAs which also serve as ADRCs, this service is targeted primarily for older adults.

- Coordinated community and institutional eligibility determination

  Through one integrated process, a person can be determined eligible for nursing facility or a range of home and community-based services crossing three funding streams (Medicaid state plan, Medicaid waiver and state-funded) and alternative delivery models (traditional agency-based and consumer directed). Medical eligibility is determined by a single state assessing service agency (ASA), through an in-home visit. A nurse from the ASA uses a standardized medical assessment tool to determine a person's clinical eligibility for nursing facility services and for all in-home services. The ASA uses the assessment to develop a service plan and, based on the individual's preferences and existing informal supports, submits the service plan to the appropriate service coordinating agency.

  Access to residential services is noteworthy for its exclusion from the Medical Eligibility Determination process. According to a 2008 analysis, as Maine reduced utilization of nursing facility services, utilization of residential services increased.[57] DHHS plans to develop eligibility criteria for accessing residential services.

- Coordinated clinical and financial eligibility

  The medical eligibility determination process is meant to be coordinated with the financial eligibility determination process, in order to match the individual with the right program. Although on separate tracks, there is communication linking the two processes. However, there can be wide variation in the time it takes to complete these two processes. In addition, there are opportunities for improving coordination between the functional and financial eligibility determination processes. Some believe the process of determining MaineCare eligibility might be sped up if the ADRCs (and AAAs) had a more consistently defined role in helping people compile the required documentation and other parts of their MaineCare application.[58]

  Under the auspices of its Systems Transformation grant and with the assistance of its Lean Management staff, DHHS has developed and is implementing work plans for streamlining these two processes and improving the format for communicating referrals and change in status.

- Person centered planning

  Planning occurs at multiple levels in the process of accessing home and community based services. The ASA develops an authorized service plan, built around an individual's need, preferences and informal supports available. In addition, the HCCA works with the individual to translate the authorized service plan into services and providers, again based on the individual's needs and preferences. Finally, the in-home provider works with the individual to provide services according to needs and preferences. At all of these stages, providers can and do work with the individual to help them identify goals and build an array of formal and informal supports to achieve those goals. However, doing so is a matter of individual practice, not a programmatic requirement.

- Tracking waiting lists

  Waiting lists are managed by several entities. There is no central waiting list for people waiting to access residential care or nursing facility services. Each facility maintains its own list and people could be on more

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[57] The Lewin Group and the Muskie School. 2008.

[58] Stakeholder Meeting. January 31, 2008. Mapping Access to Elder and Adult Services for Maine's Systems Transformation Grant.

than one list. In response to stakeholder requests, OES is currently developing criteria for prioritizing people on its waiting lists so that resources are allocated based on some consideration of need, rather than "first come, first serve."

Waiting List	Managing entity	Updating
Adult day care	OES	Monthly
Respite	AAAs	Monthly
State funded, MaineCare, MaineCare waiver HCBS	Service coordinating agency	Monthly
State-funded Independent Support Services	ISS Provider	Monthly
State-funded assessments	ASA	Monthly

Institutional Supply

- **Privacy and autonomy considered**
  Licensing standards for nursing facilities articulate the right to private communications and the right to receive visitors. Activities are individualized and group based on an individual assessment of needs and interests. However, licensing regulations do not in general place a heavy emphasis on privacy and control and do not require staff to be trained in person centered care or services.

- **Controls on supply**
  Nursing facilities must obtain a Certificate of Need for increasing the number of licensed nursing facility beds, or the number of licensed nursing beds or "swing beds" in a hospital.[59] DHHS may not accept application for any type of new nursing facility bed unless there has been a specific appropriation for new beds from the legislature. In 1999, Maine had 7,456 licensed nursing facility beds;[60] that number fell to 7130 in 2008.[61] Between 1999 and 2006, occupancy rates have increased from 89.5%[62] to 91.4%,[63] giving Maine the 11th highest occupancy rate nationally.

Transition from Institutions

- **Identifying people for transitioning**
  DHHS focuses primarily on diverting people from nursing facility services and does not currently have any initiative focused on nursing facility transition. Following its reform efforts of the 1990s, DHHS uses the single entry eligibility determination process to divert people from nursing facility care when appropriate. Persons residing in nursing facilities are reassessed periodically, to determine whether the individual continues to require nursing facility services.[64] However, these assessments are intended to identify those who must move because they are no longer eligible, not necessarily those who wish to move. In addition to identifying people who are ready to transition, DHHS is interested in gaining a better understanding of whether its diversion efforts are as effective as they could be.

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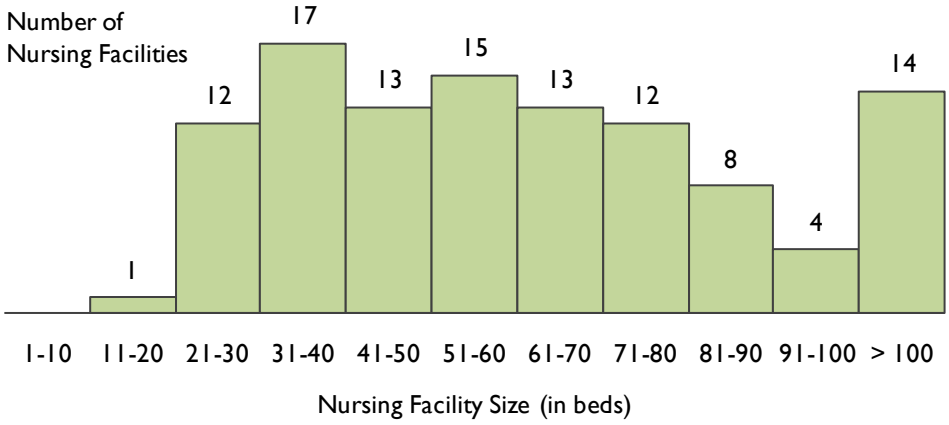
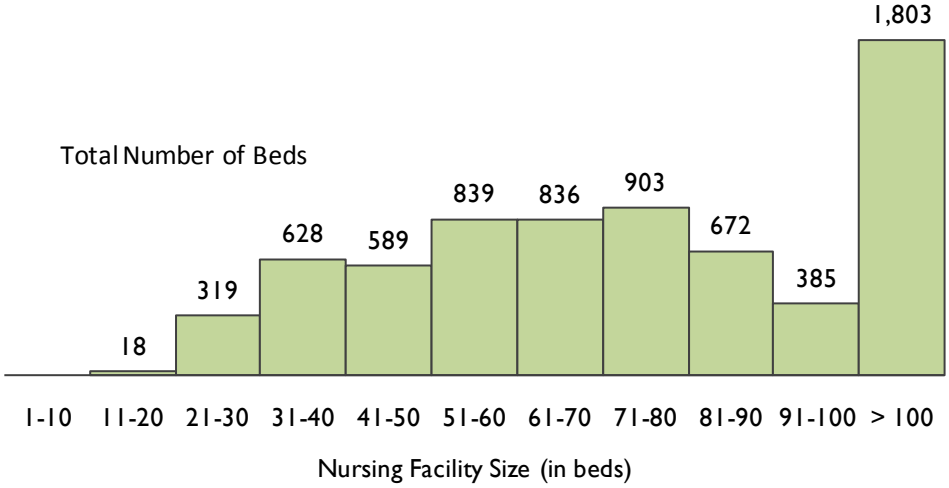
[59] 10-149 CMR Chapter 5, Office of Elder Services Policy Manual, Section 71.03(A)(5), Certificate of Need for Nursing Facility Level of Care Projects.
[60] Harrington, Charlene and Helen Carrillo, Courtney LaCava, September 2006. *Nursing Facilities, Staffing, Residents and Facility Deficiencies, Department of Social and Behavioral Sciences, 1999-2005.* Department of Social and Behavioral Sciences, University of California San Francisco.
[61] Harrington, Charlene and Helen Carrillo, Brandee Woleslagle Blank. 2008. *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2001 through 2007,* Department of Social and Behavioral Sciences, University of California San Francisco.
[62] Harrington, et al. 2006.
[63] Harrington, et al. 2008.
[64] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 67.03.

Number of Nursing Facilities in
Maine by Bed Size in 2009 (N=109)



Source: Maine Division of Licensing and Regulatory Services as of 3/26/2009

Number of Maine Nursing Facility
Beds by Facility Bed Size in 2009 (N=6,992)



Source: Maine Division of Licensing and Regulatory Services as of 3/26/2009.

- ◉ Funds transition planning
  For persons in nursing facilities who are waiting placement for MaineCare home and community based waiver or state plan services, a discharge planner can work with the in-home service coordinator to develop a home care service plan for implementation upon transition.

- ○ Funding for one-time transition expenses
  The state-funded home based care services and the MaineCare waiver program fund one-time expenses for home or environmental modifications; however, these services are not available until a person is already accessing services in the community. Funding is not available for other one-time transition costs.

Continuum of Residential Options

- ◉ Privacy and autonomy considered
  Licensing regulations for Assisted Housing articulate an individual's right to privacy and the right to choose his or her activities. The regulations require residential providers to solicit residents' preferences when planning activities and to encourage residents to participate in meal planning and to use their own furnishings in their rooms. The licensing regulations however do not place a heavy emphasis on privacy and control and do not require staff to be trained in person centered care or services.

- ● Range of options
  DHHS offers a range of residential options:

  Independent housing with services. A state-funded option, this service includes apartment living with service coordination and supportive services (homemaking services, meals, personal care, transportation and personal emergency response) provided.

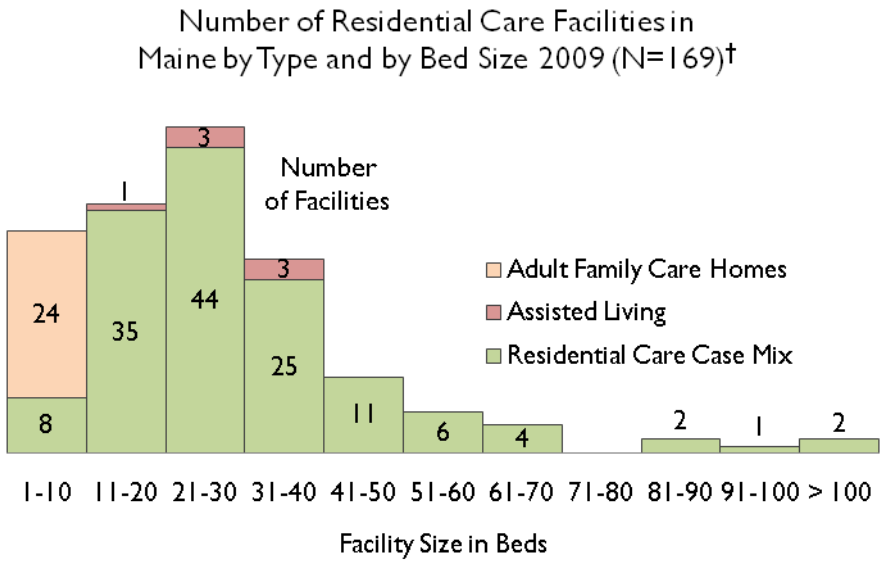
  Assisted living. Residents live in private apartments with access to common dining and may receive personal assistance, care management, medication administration and nursing services.

  Adult family care. Adult family care homes are residential care services provided in residential style home for eight or fewer residents. Residents may receive personal assistance, personal supervision, care management, and nursing services when medically necessary.

  Adult foster home. Adult foster home are residential care services provided in group settings of up to six residents. Rooms may be semi-private bedrooms, with a common living and dining area shared with the provider's family. Residents receive care coordination, transportation, nursing services when medically necessary.

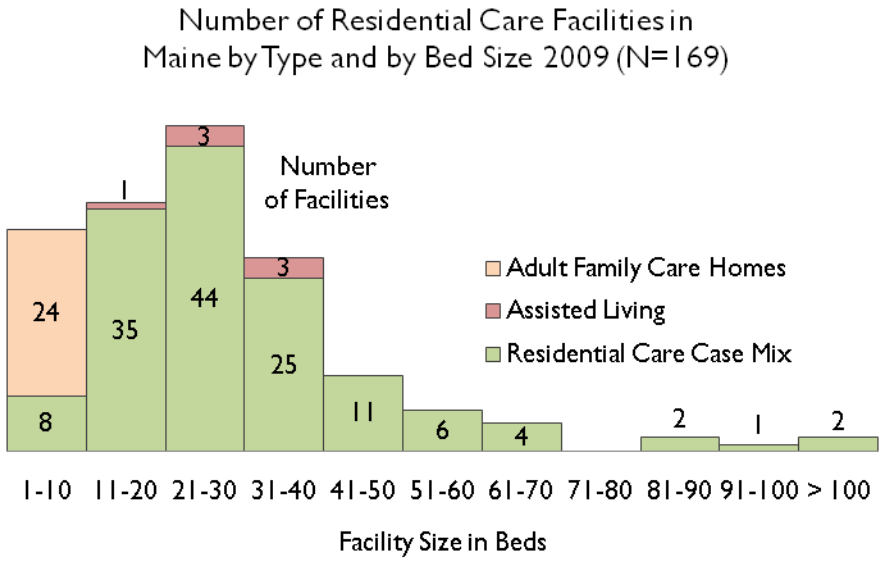
  Residential care. These services are provided to three or more residents in private or semi-private bedrooms, with a common living & dining area. The highest level of care provides staffing 24/7 staffing and a nurse is retained to observe a resident's signs and symptoms.

- ◉ Up-to-date information about available options
  Consumers can access a searchable database of licensed residential providers serving people with disabilities. This data base puts in one place, contact information, information about facility size, location and services provided, as well as populations served. However, the database is not a comprehensive listing of housing options and does not include information about current vacancies. As DHHS and MSHA move forward with the housing registry, the residential options for this population group should be included.



† "Assisted living facilities" includes the seven facilities regulated and licensed by the Maine Dept. of Health and Human Services and monitored by the Maine Office of Elder Services. This does not include all assisted living facilities in Maine.

Sources: Muskie School Residential Care Facility MDS Database and the Maine Office of Elder Services



† "Assisted living facilities" includes the seven facilities regulated and licensed by the Maine Dept. of Health and Human Services and monitored by the Maine Office of Elder Services. This does not include all assisted living facilities in Maine.

Sources: Muskie School Residential Care Facility MDS Database and the Maine Office of Elder Services

Long Term Services and Supports Infrastructure Development

- **Case management**
  The Home Care Coordinating Agency provides case management services to those people who qualify for home based services.

- **Develops workforce to meet needs**
  DHHS has developed standards for a 40-hour training requirement and qualifying exam for Personal Support Specialists, the unlicensed entry level personnel providing personal assistance under agency-based programs. In addition, DHHS has developed a standardized curriculum for a Certified Residential Medication Aide (CRMA). For the consumer directed program, the service coordinating agency supports consumer training for hiring and managing competent workers.

  DHHS also tries to address the supply of workers. Under its 2001 Real Choices Systems Change grant, DHHS helped to develop a workers' association which has become a national model for supporting and addressing the needs of direct support workers.[65] Maine continues to focus on the importance of a strong direct care workforce as a key component in sustaining its long term care system. In 2006, the 122nd Maine legislature enacted two resolves that directed the Maine Department of Health and Human services to conduct a study of direct care workers in state-funded and MaineCare funded programs in conjunction with the Maine Department of Labor and to report back on efforts to increase the availability of workers for homemaker and home-based care programs administered by the Office of Elder Services. A Study of Maine's Direct Care Workforce was submitted to the 123rd legislature in March 2007. This study brought attention to the increasing demand for frontline workers and the inadequacy of the wage and benefit levels of these workers compared to other entry level jobs. The report made recommendations for improving the direct care workforce in Maine. The focus on the direct care workforce has continued under a cooperative agreement with the Muskie School to review the methods for setting and updating rates across Maine's long term care programs and the implications for wages, benefits and training. This work also includes the development of a profile of the functions, qualifications and training paths for direct care workers. This task is complicated by the varying titles, competencies, functions performed by direct care workers.

- **Support for informal caregivers**
  Through the AAAs, OES administers a number of services and supports for family caregivers. The Partners in Caring Program provides respite and other services for those providing care to people with dementia. The Family Caregiver Support program provides information, assistance and other services to caregivers of older adults. In addition, OES administers a state-funded Best Friends™ training program for Alzheimer's Care.

OES Caregiver Programs

Adults with Dementia	Number Served
Partners in Caring Respite Program	
▪ respite (in-home, family/friend, out-of-home and adult day)	422
▪ information and support	1,234
Best Friends™ Training Program	123
Older Adults	**Number Served**
Family Caregiver Program	
▪ counseling, support, and training	3,261
▪ respite services	131
▪ supplemental services	230
▪ information	819
▪ assistance	3,186
LD-519 Demonstration Project	258

[65] For more information, see the website for the Maine Personal Assistance Services Association at http://www.mainepasa.org/

This program trains caregivers and providers on using the values and principles of friendship to care for persons with dementia. In addition, OES has piloted a state-funded program that provides funding for up to a $1,000 to caregivers for respite, assistive technology, home modifications, individual or household needs, homemaker services, health maintenance, therapies, "community connection" services, etc. OES is hoping this program will be continued by the Legislature.

- Uses evidence based practices

DHHS has piloted a number of evidence-base practices aimed at improving community services or caregiver supports. DHHS implemented Healthy IDEAS, an evidence-base program designed to reduce depressive symptoms in older adults. This program was implemented through a demonstration grant by case managers for people on the HCBS waiver. It has moved from a demonstration program to one that has become integrated into the ongoing practice of case managers. The program has also been modified and expanded for use with caregivers of people with dementia. This program is being implemented through Maine's area agencies on aging. Under an 18-month Alzheimer's Disease Support Services Program Innovation Grant, DHHS will study the impact of services on diverting nursing/residential care admissions.

Evidence Based Practice	Status
Healthy Ideas for HCBS Recipients	Pilot 2007-08 Statewide 2009
Healthy Ideas for Caregivers of People with Dementia	Pilot 2007-08 Statewide 2009
Chronic Disease Self-Management	Pilot 2006-08 Statewide 2009
A Matter of Balance	Pilot 2006-08 Statewide 2009
Enhance Wellness	Pilot 2006-08 Statewide 2009
Enhance Fitness	Pilot 2006-08 Statewide 2009
Savvy Caregiver	Pilot 2009-11

Under a 2006 grant, DHHS is collaborating with MaineHealth's Partnership for Healthy Aging, the area agencies on aging, and other community partners, to advance evidence-based prevention and wellness programs in Maine. DHHS is also implementing and disseminating evidence-based programs that empower older people to take more control of their own health through life style and behavioral changes, including Living Well, A Matter of Balance, Healthy Ideas, Enhance Wellness, and Enhance Fitness.

Maine is currently piloting the Savvy Caregiver Program, an evidence-based, training intervention to improve the knowledge, skills and well-being of caregivers in order to help them provide care and use services and supports that will keep their family members with dementia living in the community for as long as possible.

- Stakeholders participate in planning for services

On an ongoing basis, OES solicits feedback from stakeholders through its Office of Elder Services Advisory Committee. In addition, in 2006 OES sponsored a "Blaine House Conference on Aging" which began with 15 local forums and then a statewide event in which delegates voted on 25 resolutions relating to caregivers (paid and unpaid), community involvement and volunteerism, creative housing and services, elder abuse, employment, healthy aging, and transportation. These resolutions have been used to shape OES priorities going forward. OES held another Blaine House Conference on Aging in 2008 where resolutions from 2006 were reviewed and updated. OES also engages stakeholders through public hearings on its State Plan on Aging, which is developed every four years.

Consumer Direction

- Individualized budget
  DHHS uses standardized or case-mix adjusted rates for the majority of the services it provides.

- Option to hire own workers
  The consumer-directed programs allow the consumers to hire their own direct care workers. Eligibility for this program is conditioned on the individual's cognitive capacity to self-direct. The HCCA provides training and other support for consumers recruiting, hiring and firing their own workers and serves as the fiscal intermediary for payroll and other employer functions.

  The Family Provider Service Option (FPSO), available under the traditional agency-based programs allows an individual, 21 years or older, to register as a personal care agency solely for the purpose of managing the individual's own services or the services of up to two family members. The FPSO Employer hires and directs workers, works with a fiscal intermediary to provide payment to workers, keeps consumer and personnel records, maintains workers' compensation insurance (paid for with program funds) and works closely with the HCCA care manager. The HCCA managing this consumer-directed option also oversees service plan implementation for agency-based home care services.

  To participate, the individual or family member must register as Personal Care Attendant Agency with the Division of Licensing and Regulatory Services and participate in a 4-hour training program. Currently 189 people are using this option. DHHS is looking at this model to determine how it might be changed to streamline access and availability.

- Option to purchase goods and services
  Under the Medicaid programs, consumers do not have the option to manage their service budget or purchase goods and services outside the standard service package. In previous years, Maine had experimented with a cash benefit for its state-funded program, but discontinued that option. Maine's respite program does allow a one-time purchase of up to $3,500/year.

Quality Management

- Quality management plan
  OES and OACPDS are responsible for quality management plans as part of the HCBS waiver applications. State-funded services are monitored by OES based on standards set in their provider contracts. DHHS continues to clarify the roles and responsibilities of quality review across its programs. Certain quality assurance activities are clearly defined for contracted entities. OES and OACPDS have met with the Office of MaineCare Services to look at consistency and possible standardization in reporting on the quality assurances for the two waivers serving this population.

- Quality measurement
  OES identified indicators for the federal assurances under its waiver. OACPDS will be identifying quality indicators during its upcoming waiver renewal process. Performance measures are included in HCCA and ASA contracts to ensure quality performance in assisting consumers accessing services. Contract requirements include quarterly reporting on program census, consumer complaints, and service utilization. Nursing home quality measurements include the national quality indicators developed and reported by CMS. These are used for national comparisons and for use in surveys of nursing homes. Maine has developed a similar set of quality indicators for residential care facilities. All residential care facilities in Maine must complete an assessment instrument, called the MDS-RCA. From this assessment are computed a set of quality measures that were developed by DHHS and industry representatives. Each facility receives a report of its quality indicators compared to a peer group and statewide averages.

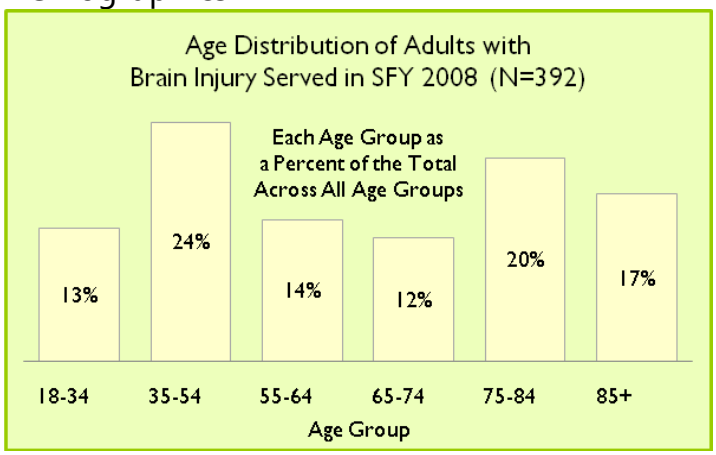
- Consumer surveys

  A survey of consumers in nursing homes was done in 2005; this survey has not been updated in recent years. In-home consumer surveys were conducted in 2005 by an independent entity. Satisfaction surveys are also conducted annually by the HCCA. OES is planning to do mailed surveys to its home care consumers this year. It is also planning to do a survey of workers who provide services in the home.

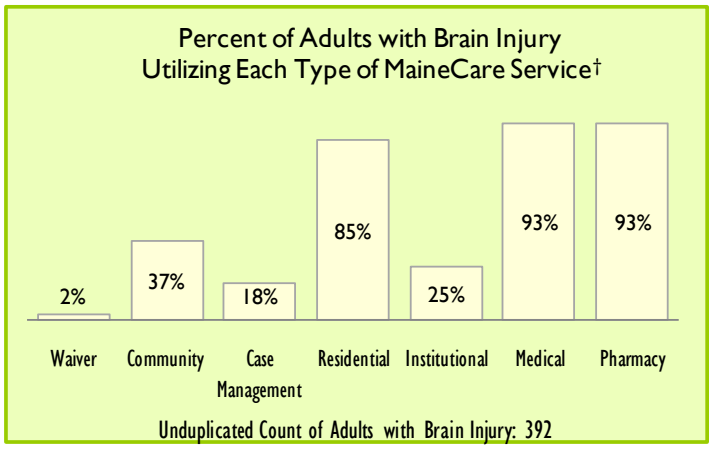
Adults with Brain Injury

Adults with Brain Injury

Demographics



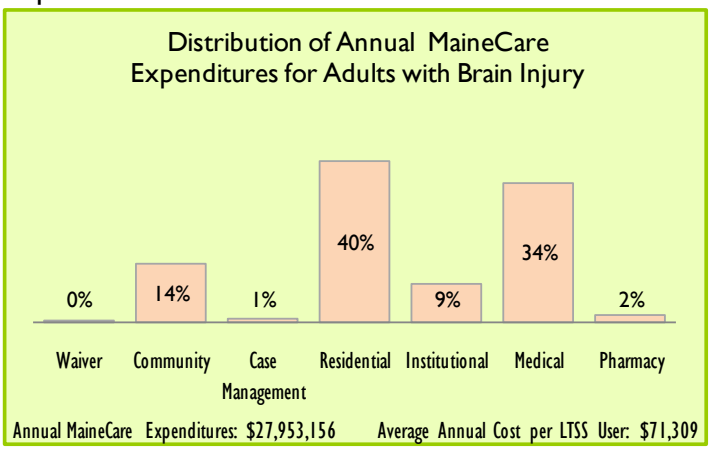
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- This analysis identified 392 people with brain injury who are long term service users.
- 85% of people in this group are being served primarily in residential settings and 25% in institutional settings.
- 300 of the 392 people in this group are also in the Older Adults and Adults with Disabilities group; 9 are in adults with mental illness group; and 18 are in one of three or four of the other groups.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- The cost of residential care (40%) is the largest component of total MaineCare expenditures for this group.
- Medical costs represent almost one-third of total expenditures. These are largely driven by hospital inpatient costs.

System Strengths

Clear Vision. While still a very young program, DHHS has a defined and clear vision for developing and improving its long term support system for this population group and has a dedicated staff person to guide implementation.

Investment in Foundational Components. DHHS is investing in workforce development, evidence based practice and data capacity as foundational system components.

Strong Stakeholder Advisory Group. DHHS works with a strong stakeholder advisory group, whose role is built into statute.

Areas for Further Examination

Service Gaps. DHHS has identified significant service gaps for this population group, including the lack of access to case management services; an inadequate continuum of residential options; and limited access to psychosocial rehabilitative services. DHHS is exploring the feasibility of developing a waiver program to meet these needs.

Out of State Placements. DHHS has identified a number of people with brain injury in out-of-state placements and would like to develop strategies for bringing these people back to Maine.

DEFINITIONS AND DATA

Adults with brain injury with a continuing need for services were identified by the use of neuro-rehabilitative services; the use of specialized nursing facilities for persons with brain injury; individuals accessing residential care with a brain injury diagnosis;[66] and members with inpatient hospitalization over 30 days or 8 or more emergency department visits during the year with a brain injury diagnosis.

NOTE: This definition includes very specific diagnosis and utilization criteria that were used to identify long term service and support users. DHHS considers the number of people with brain injury reported in this analysis to be low. Prior studies have identified up to 2000 people with brain injury – although they may not have a long term service need. The current definition may be refined after further analysis.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. Adult members may be in more than one office population; therefore, adult office populations should not be added. Adult totals shown here have been aggregated as distinct counts and dollars.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

[66] Brain injury diagnosis listing was developed by the Maine Center for Disease Control and Brain Injury Service Unit. A listing is available on request.

Adults with Brain Injury

Until recently, persons with brain injury have been treated as a subset of the elder and adult population described in the previous section, assuming there is no co-occurring diagnosis making a person eligible for mental health or developmental services. This section focuses in on this subset as an emerging population group that DHHS and others have long recognized as underserved by existing public programs.

With medical advances in treating head injuries on the "front end" – when the injury occurs – the number of people surviving with a head trauma has increased significantly over the years. Unfortunately, there has not been the same level of progress on the "back end" of an injury – the survival rate exceeds the rate of successful rehabilitation and the service system has not developed the capacity to provide the needed long term services and supports.

Defining the population of persons with brain injury is challenging, partly because brain injury can be difficult to diagnose. It can also be hard to generalize about the impact of a brain injury on a person's functioning and rehabilitation can vary widely. A brain injury can impact an individual's self-awareness, judgment, personality, memory and other cognitive and behavioral functions. In some cases a brain injury might be associated with a physical injury; in other cases there might be no physical sign of disability. The impact can also vary over time. Many people with a brain injury benefit from rehabilitative services and return to their previous life, although usually with some adjustment. However, some people can experience life long disability causing loss of employment, independence, and community roles. Of this group, DHHS reports many do not enter DHHS' service system until after they have exhausted their private formal and informal supports.[67] In addition, a small but important subset of persons with brain injury develops aggressive or difficult behaviors.[68]

As a result, a person with a brain injury might need a range of services, including rehabilitative and transitional services while recovering from an injury or, for a person with a life long impairment, long term services and supports of varying types and intensity, depending on the nature of a person's brain injury.

Programs and Services

DHHS is in the early stages of building a brain injury program. In 2005, the Legislature designated DHHS as the state agency responsible for acquired brain injury services.[69] However, it is only since 2007, when Brain Injury Services became a new program within the Office of Cognitive and Physical Disability Services (OACPD), that DHHS has had a defined program for brain injury services. Prior to this time, policymaking for brain injury services was done by the predecessor to the current Office of Elder Services.

DHHS, advocates, providers and consumers built the foundation for this program incrementally over a number of years, starting in the 1980s. A 2003 planning grant from U.S. Health Resources and Services Administration (HRSA) played an important role in raising the visibility of this population group in the eyes of the Legislature and others. A Brain Injury Advisory Council oversaw the completion of a series of focus groups, interviews and surveys to assess needs and resources for this population group. More recently, the new Brian Injury Services program has developed a comprehensive plan for brain injury services, identifying a series of services gaps. The

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[67] Gary Wolcott, Program Manager, Brain Injury Services. Phone conversation. February 19, 2008.
[68] Maine Department of Health and Human Services, Brain Injury Services. 2008. Plan for Brain Injury Services: 2008-2009. Report to the Legislature (citing unpublished work of Marty McMorrow accessed at nashia.org/conferences/sos/2007sosmcmorrowbehavioral.pps).
[69] 22 MRSA §3089.

only proposed DHHS service expansion in the Governor's budget this year was for residential services in northern Maine.

Services

The Legislature defines brain injury, or "head injury" as "an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which:

- Is not of a degenerative or congenital nature;
- Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning;
- Can result in the disturbance of behavioral or emotional functioning;
- Can be either temporary or permanent; and
- Can cause partial or total functional disability or psychosocial maladjustment."[70]

For this group, DHHS covers three groups of services specially designed for persons with brain injury, all of which are MaineCare funded:

- Rehabilitation services
- Specialized residential services
- Specialized nursing facility services

When eligible, people with brain injury may also access services available through other programs, including those described in OLDER ADULTS AND ADULTS WITH DISABILITIES and ADULTS WITH BRAIN INJURY. (Analysis for this profile showed that 300 of the 392 people in the brain injury population were also in the older adults and adults with disabilities group. However, service gaps include:

- Service coordination or case management services
- Daily living services to meet the needs of this group
- Psychosocial rehabilitative services
- Supported apartments

DHHS is exploring the feasibility of developing a home and community-based waiver for persons with brain injury as one strategy for beginning to address these service gaps.

Delivery System

There is not an organized delivery system for providing long term services and supports to this population group. Service coordination is not a funded service unless a person is eligible for case management services through another program. See ROLES IN THE DELIVERY SYSTEM for more information.

Waiting Lists

Currently DHHS has a list of 34 people waiting to access residential services.

[70] 22 MRSA §3086.

Brain Injury Services	Target Population	Funding Source
Treatment Services		
Rehabilitation Services. Rehabilitation services are provided under the direction of a neuropsychologist or physician and delivered by a neuropsychologist, physician, occupational therapist, physical therapist, registered nurse, speech-language pathologist, or other qualified staff.[71] Depending on eligibility, a person can access one of three levels of rehabilitation services: intensive, post-acute and day health rehabilitative services. Each of the three levels of services has different caps on the number of hours per week as well as reimbursement.	Persons with brain injury	MaineCare §102
Residential Services		
Residential Services. MaineCare covers residential services with intensive rehabilitative and community support services for persons with acquired brain injury. The admission criteria used by each residential provider varies and will be based on diagnosis and medical necessity.	Persons with brain injury	MaineCare §97
Hospital & Institutional Services		
Specialized Nursing Facility Services: MaineCare covers intensive rehabilitation nursing facility services for persons with brain injury.[72] An assessment by DHHS' independent assessing service agency applies a Disability Rating Scale that measures a person's awareness and responsiveness, cognitive ability for self-care, dependence on others, and psychosocial adaptability. A person is eligible if their level of disability is sufficiently severe but falls short of a vegetative state.	Persons with brain injury requiring nursing facility level of care	MaineCare §67

Roles in the Delivery System	
Roles	*Description*
Eligible Persons	A person with a brain injury.
I&R / Outreach / Referral Sources	A hospital, a nursing facility, a residential provider, doctor, or other provider, self-referred, family members, the Brain Injury Association, protective services, care managers (any systems), legal services, mental health providers, Aging and Disability Resource Centers, 211 Maine, schools, the VA or Veterans Services.
Case Manager	Not available unless funded through another program, if eligible.
Service Providers	Rehabilitation provider, nursing facilities, residential providers. (Providers funded through other programs may also be involved.)
Utilization Manager	The assessing services agency (ASA) conducts the eligibility determination for nursing facility services. DHHS' Brain Injury Services reviews the eligibility determination for rehabilitation services. There is no utilization management function for residential services.

[71] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter 2, Section 102.
[72] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter 2, Section 67.02-5.

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✕	Not Relevant to Population Group

Strategic Vision for a Balanced System

● Vision statement

The Legislature articulated a vision for brain injury services when it required DHHS to develop a comprehensive plan for addressing the needs of persons with brain injuries. The Legislature wanted the planning process to include a thorough evaluation of waiver and other Medicaid programs that promote community integration.[73] DHHS' plan was developed with the intent of integrating services to achieve the most efficient use of resources while fulfilling its mission of providing high quality services for the health and safety of all Maine citizens.[74]

● Monitors progress toward vision

The Legislature plays an important monitoring role. It has established DHHS' obligation to provide periodic progress reports on the elements of its plan. It has also established under law a Brain Injury Advisory Council to provide independent oversight and advice, including recommendations on the status and effectiveness of the array of brain injury services.[75] As part of the process for developing this profile, DHHS has developed agreed upon definitions for population groups, services and units of service.

Consolidated State Agency

○ Shifting resources

DHHS can not shift resources across nursing facility and residential or community settings in the same budget cycle. In addition, for persons with brain injury, the inability to shift resources from an out-of-state placement to an in-state placement is also a major issue. In 2007, DHHS' care management contractor conducted case reviews for 45 Maine residents being served in out-of-state placements.[76] Their findings showed that:

- 90% of the people served out of state had traumatic brain injuries.
- The majority are appropriate for community placement.
- No evidence was found that complex medical needs alone were the reason for out-of-state placement.

Instead the study showed that behavioral issues associated with complex medical needs, which cannot be safely managed at in-state reimbursement rates, are the primary reason people are served out of state. Out-of-state placements are reimbursed at a higher rate than they would be if provided in state. As a result, the

[73] P.L. 2007, Chapter 105, *Resolve, To Promote Community Integration for Individuals with Brain Injury*

[74] Maine Department of Health and Human Services, Brain Injury Services. 2008. Plan for Brain Injury Services: 2008-2009. Report to the Legislature.

[75] 34-B MRSA §19001.

[76] Schaller Anderson. November 2007. Evaluation of Maine Residents Residing in Out-of-State Facilities.

legislative allocation of money for out-of-state care cannot be used to provide the same level of service (for possibly less cost) in Maine and closer to home.

- Coordinated policymaking
  Accountability and responsibility for policymaking is dispersed across DHHS and the Office of Brain Injury Services is responsible for coordinating these multiple points of accountability. This responsibility, carried out by one staff person, requires bridging multiple offices within DHHS, including the Office of Elder Services, Developmental Services, the Office of Adult Mental Health Services, the Office of MaineCare Services and others. The director of OACPDS represents brain injury services in coordination discussions at the IMT. Coordinated policymaking is a work in progress. Brain Injury Services has been in existence only since 2007 and is engaged at a number of levels and across multiple organizational units of DHHS. In the long term, DHHS envisions Brain Injury Services growing into a more comprehensive program, integrated with existing services.

- Uses data to plan for services
  DHHS is using grant funds to develop its data and analytical capacity. It is working to transcribe data from paper Brain Injury Assessment Tools (a standardized assessment tool completed as part of the eligibility determination process for rehabilitation services) into an electronic database. This data provide a snapshot of a person's status every 6 months and can help DHHS understand better the needs of the people it serves. It can also be linked with data from other programs to get a better understanding of the other dimensions of service utilization and outcomes.

Single Access Points

- Information and referral
  There appears to be an unmet need for information and referral for this population group. A survey conducted in 2004, indicated that consumers lack information about available options, making it harder to access services.[77] In focus groups conducted as part of that same study, consumers reported that medical professionals often lack knowledge about community resources and often do not understand the ramifications of brain injury, meaning that many people are sent home without understanding available resources, who to call or what to expect..[78] DHHS provides a small amount of funding to the Brain Injury Association of Maine to provide hotline services for people with brain injury. However, these services are inadequate given the need.

  Maine's ADRCs were designed to serve all adults of any type of disability. However, Maine's pilot ADRCs have established varying levels of visibility and limited capacity for serving people with brain injury. If Maine proceeds with defining an ongoing role for the ADRCs, part of that expansion could include specialized training for serving persons with brain injury.

- Linking with services
  For people with brain injury there is no access to case management services and there is not another systematic process for linking people to needed services and supports. There is no system resource available to help people navigate private and public insurance options, or to make them aware of the potential array of services that might be available to them. The hotline provided by the Brain Injury Association provides some assistance but it is insufficient to meet the need.

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[77] Brain Injury Association of Maine. 2005. The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine: Survey Findings.
[78] Ibid.

- Coordinated community and institutional eligibility determination
  The process of determining eligibility for nursing facility services is coordinated with eligibility for home and community based services for older adults and adults with disabilities. However, for persons with brain injury home and community based options designed for older adults and adults with disabilities do not offer a viable community option for most people with brain injury. These services are focused more on meeting needs for physical assistance and do not provide the level of cognitive and behavioral supports needed. Access to rehabilitation day services is not coordinated with this process.

- Coordinated clinical and financial eligibility
  The process of determining financial eligibility is separate from the clinical eligibility determination for rehabilitation. When eligibility is based on the ability to document a disability with medical records, the process may be more cumbersome. In the absence of a coordinated process, access would be smoother if consumers had assistance in preparing a MaineCare application that involves documenting a disability.

- Person centered planning
  People with brain injury do not have access to case management services (unless they qualify under another program) to coordinate access to services, and develop a full understanding of the range of an individual's needs. Person centered planning is integral to the specialized residential programs and rehabilitation services. For example, for rehabilitation services, the planning must be individualized, taking into account personal preferences and the interdisciplinary team includes the consumer and family members.[79]

- Tracking waiting lists
  Brain Injury Services maintains a voluntary waiting list established through collaboration with residential providers. BIS plans to formalize requirements for maintaining and tracking waiting lists going forward.

Institutional Supply

- Privacy and autonomy considered
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

- Controls on supply
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

Transition from Institutions

- Identifying people for transitioning
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury: DHHS identified people with brain injury in out-of-state settings and in in-state residential settings who could successfully transition to a more integrated setting. In addition to the study of persons in out-of-state placements discussed above, in a 2007 two-part study, 81 of the 103 individuals then living in Maine's specialized residential settings were assessed to determine their readiness for a more independent setting. According to the study, a minimum of 16 and as many as 29 people were ready to move to a less restrictive, less supervised level of care.[80]

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[79] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, §102 Rehabilitative Services.
[80] Maine Department of Health and Human Services, 2008. Report to Joint Standing Committee on Health and Human Services Pursuant to Chapter 61, Resolve, to Ensure Proper Levels of Care for the Elderly and the Disabled.

- ○ Funds transition planning
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

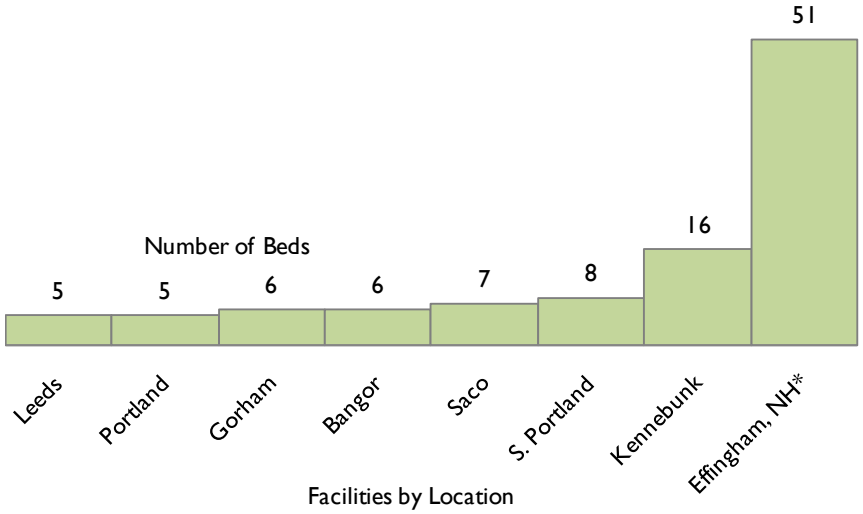
- ◉ Funding for one-time transition expenses
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

Continuum of Residential Options

- ◉ Privacy and autonomy considered
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

- ◉ Range of options
  Gaps in the array of residential services create a barrier to service for people with brain injury. For persons with brain injury, there is nothing in between 24/7 specialized residential services and living in the community with natural supports.[81] For a number of people identified as ready to move to supportive housing those services were not available. DHHS reports that, because transitions out of residential facilities are less than 5% per year, few openings are available to support transitions from higher levels of care, foreclosing options for those ready for discharge from acute care and institutional settings. Geographic availability is also a major issue for residential services, with the northern half of the state having no specialized residential services at all. As a first step in addressing this gap, the only expansion of services in the Governor's budget this year was funding for residential services in northern Maine.

Maine In-State Providers of Assisted Living Services to Persons with Brain Injury, by Bed Size and Location 2008 (N=8)



*The Lakeview facility in Effingham, New Hampshire located 15 miles from Maine, is considered an in-state provider.

Source: Maine Department of Health and Human Services, Brain Injury Services. 2008. Plan for Brain Injury Services: 2008-2009. Report to the Legislature.

[81] Maine Department of Health and Human Services, Brain Injury Services. 2008. Plan for Brain Injury Services: 2008-2009. Report to the Legislature.

- **Up-to-date information about available options**
  The information in OLDER ADULTS AND ADULTS WITH DISABILITIES applies equally to services for people with brain injury.

Long Term Services and Supports Infrastructure Development

- **Case management**
  Case management services are not available to persons with a brain injury unless they qualify through a different program (*e.g.*, public guardianship, community support for persons with serious and persistent mental illness, or a case manager in the developmental services system). Case management services has been identified as a critical service missing from the brain injury delivery system [82] and is included as part of DHHS' comprehensive plan for building brain injury services.

- **Develops workforce to meet needs**
  DHHS is working with Acadia Hospital at Eastern Maine Medical Center to develop a curriculum that will incorporate best practice for serving people with brain injury into training for paraprofessionals. DHHS has also offered training and scholarships to double the number of Certified Brain Injury Specialists in the state. This initiative was paid for with grant funds; however it is now becoming self-sustaining with providers voluntarily initiating the training and offering lower cost for the certification exam with a "bulk" purchase.

  In spite of these efforts, the training of professionals and direct care workers is still considered a major issue: "A lack of sufficient knowledge, training and skill among Maine's healthcare, mental health and education professionals" were the leading issues identified by the Brain Injury Advisory Council in its most recent report.[83] The misidentification of brain injury and the lack of skills for responding to behavioral needs were among several issues identified. DHHS is evaluating the standards it would apply to the direct care workforce under a waiver program and for residential services.

- **Support for informal caregivers**
  DHHS reports: "When a family member receives a brain injury, the entire family is disrupted emotionally and economically. With increasingly limited health care benefits, shorter hospital stays and the high cost of in-home care, family members are often required to leave their jobs to care for a loved one at home. This combination of factors leaves families in significant need of support, guidance, and targeted services to weather this extremely difficult experience." These supports are limited or not available.[84]

- **Uses evidence based practices**
  With grant funding, DHHS is working with Dartmouth Medical School to develop white papers on evidence-based practice in three areas:

  - Behavioral support
  - Treatment for mild traumatic brain injury
  - Long term medical and psychosocial rehabilitation

  These white papers are expected to inform policy and practice in the future.

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[82] Brain Injury Association of Maine. 2005. The Silent Epidemic: Traumatic Brain Injury Services, Experiences and Expectations in Maine: Survey Findings.
[83] Brain Injury Advisory Council. 2009. Brain Injury in Maine: A Growing Public Health Issue. 200702008 Report.
[84] Brain Injury Association of Maine. 2005.

- Stakeholders participate in planning for services
  DHHS provides administrative support to the Acquired Brain Injury Advisory Council, which is legislatively authorized to make recommendations for improving brain injury services.[85] In addition, in developing its comprehensive plan for brain injury services, DHHS engaged in extensive public hearings.

Consumer Direction

Consumer direction is available for persons who access the home and community based services for OLDER ADULTS AND ADULTS WITH DISABILITIES. However, eligibility for the consumer directed services available to persons with a physical disability is conditioned on meeting criteria for cognitive ability; persons with brain injury are less likely to satisfy these criteria. Specialized consumer directed home and community based services are not available for this population group.

Quality Management

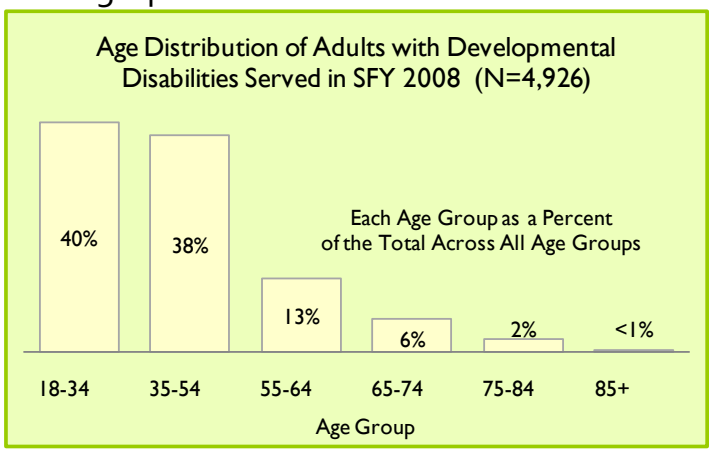
At this point, DHHS is only beginning to build quality management capacity for the brain injury program. If DHHS decides to move forward with a waiver for brain injury services, it will build a quality management system as part of a waiver program.

[85] 34-B MRSA §19001.

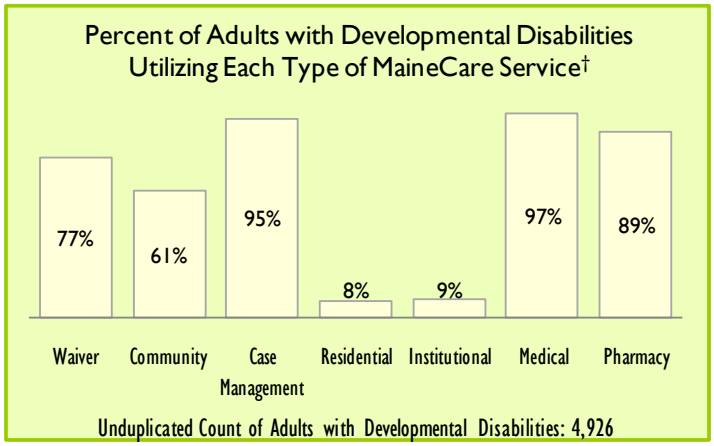
Adults with Developmental Disabilities

Adults with Developmental Disabilities

Demographics



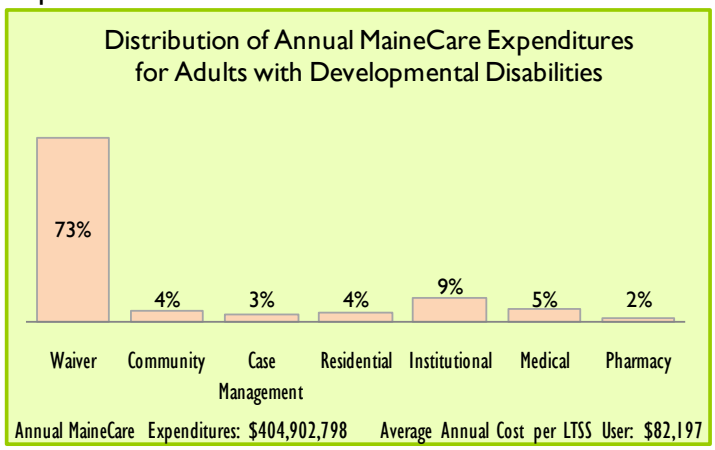
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- 77% of this population group used waiver services, 9% used ICF-MR services.
- 95% of this population group accessed case management services, 97% accessed other medical services, and 89% accessed pharmacy.
- 279 members in this group were also identified as in the Older Adults and Adults with Disabilities group.
- 246 members in this group were also identified as in adults with mental illness group.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- Expenditures for waiver services represent the largest category of MaineCare costs. Residential services are included as part of one of the two waiver programs available to this population group.

System Strengths

Commitment to Community. DHHS has a commitment to serving this population group in home and community based services, as reflected in its authorizing legislation, and backed up by the low number of people in institutional or residential settings.

Consolidated Accountability. DHHS has built consolidated accountability for the full range of services in one agency. That agency also has the flexibility of shifting resources from institutional to community services.

Person Centered Planning. DHHS has a highly developed person centered planning approach.

Areas for Further Examination

Consumer Direction. Although it has done much of the planning work necessary for implementation, DHHS does not currently offer a consumer directed option to this population group.

DEFINITIONS AND DATA

Adults with developmental disabilities includes members in ICFs-MR; accessing one of the waivers for persons with mental retardation or autism; accessing case management for persons with mental retardation or autism; accessing residential services for persons with mental retardation; or residing in a nursing home with a diagnosis of mental retardation.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. Adult members may be in more than one office population; therefore, adult office populations should not be added. Adult totals shown here have been aggregated as distinct counts and dollars.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

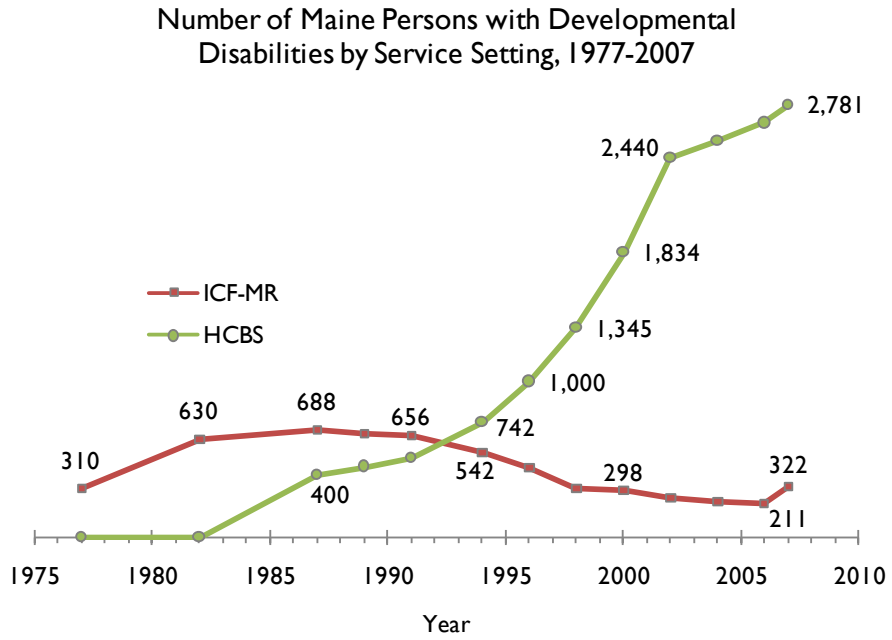
Adults with Developmental Disabilities

In Maine, developmental services for adults are available only to persons with a diagnosis of mental retardation or autism.[86] Persons with mental retardation may need help with activities of daily living, decision making, and other aspects of independent living. The majority of persons with mental retardation can live with some degree of independence, with support. Others need a higher level of assistance, some requiring total supervision and support for daily living activities. Similarly, the severity of autism can vary greatly. Autism affects the way a person comprehends, communicates and relates to others. Some adults with autism are able to work and live independently. Others may require a higher level of support.

Persons with mental retardation or autism can have co-occurring conditions including mental and physical health conditions. People entering the adult service system usually are teens or young adults transitioning from the children's service system. Unlike people who grew up in institutions, today's youth have grown up in their own community with the expectation they will continue to live and work in their community.

Programs and Services

Early phases of de-institutionalization began in the 1950s and accelerated in the late 1970s, sped up a class action law suit filed in 1975. The suit challenged the conditions at Pineland, Maine's only state-operated institution for persons with developmental disabilities. From a peak of 1500 in the 1950s, the number of people residing at Pineland was reduced to 370 in 1980;[87] Pineland was closed in 1996. DHHS has continued to shift services to the community.



Source: Prouty, Robert W., et al. 2008. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007, p. 119. Research and Training Center on Community Living, University of Minnesota.

[86] DHHS now uses the term "developmental services" to describe its programs. However, the terms "mental retardation" and "autism" are still used in statute and rule. This document uses these latter terms when the context requires their specificity. Otherwise, the term "developmental services" and "developmental disability" are used where possible.
[87] Kimball, Richard S. 2001. *Pineland's Past: The first one hundred years*. Portsmouth, NH: Peter E. Randall..

The settlement agreement for the litigation started in the 1975 was replaced in 1994 by a new consent decree still in place today. There are 763 class members[88] still under its protection. The Consent Decree sets standards for DHHS' system of community services, including person centered planning, crisis prevention and intervention, professional services to be provided, resource development and family and respite services.

In 1983, Maine developed a MaineCare waiver program to provide 400 new community placements to serve people moving out of Pineland, Maine's state-operated institution serving people with developmental disabilities.[89] As a result, this waiver was designed to meet the needs of people moving out of the institution without a home or community to go back to; it provides a comprehensive package of services, including residential services. Today this comprehensive waiver program serves up to 2860. DHHS recently developed a second waiver package that assumes that the individual is already living independently or with a natural support system; this waiver provides community supports and employment services and can serve up to 2000 people. DHHS has placed a priority on community inclusion. In 2008, DHHS discontinued funding for sheltered employment services.[90] DHHS is also exploring strategies for improving community relationships for the people it serves.[91]

Services

Services available for this population group include case management, home and community-based waiver services, residential services, and ICF-MR services. The cost of services under the waivers cannot exceed 300% of the costs of an ICF-MR for any one individual. These services are described in more detail on the page 95.

Eligibility

Access to different developmental services is tied to different tiers of criteria.

> *Diagnosis*. A diagnosis of mental retardation or autistic disorder is the first threshold that must be met before accessing any developmental services.
>
> *ICF-MR Level of Care*. To access waiver or ICF-MR services, a person must meet the medical eligibility criteria for admission to an ICF-MR.
>
> *Need for Protective Services*. Although not technically eligibility criteria, DHHS reserves a portion of waiver slots for its comprehensive waiver for those persons requiring protective services or transitioning out of an ICF/MR or other institutional setting.[92] In practical terms, this means that the comprehensive waiver is largely closed except to those requiring adult protective services or at risk of abuse. Currently, this waiver is completely closed to new enrollments.

Most people in this population group qualify for MaineCare based on their eligibility for SSI.

The Delivery System

Developmental services are accessed primarily through DHHS district offices. DHHS contacts with community providers for services. See the grid on the next page.

Waiting Lists

The comprehensive waiver is closed to new members.[93] Currently there are 120 people on the waiting list for this waiver. The Community Supports waiver (§29) does not have a waiting list.

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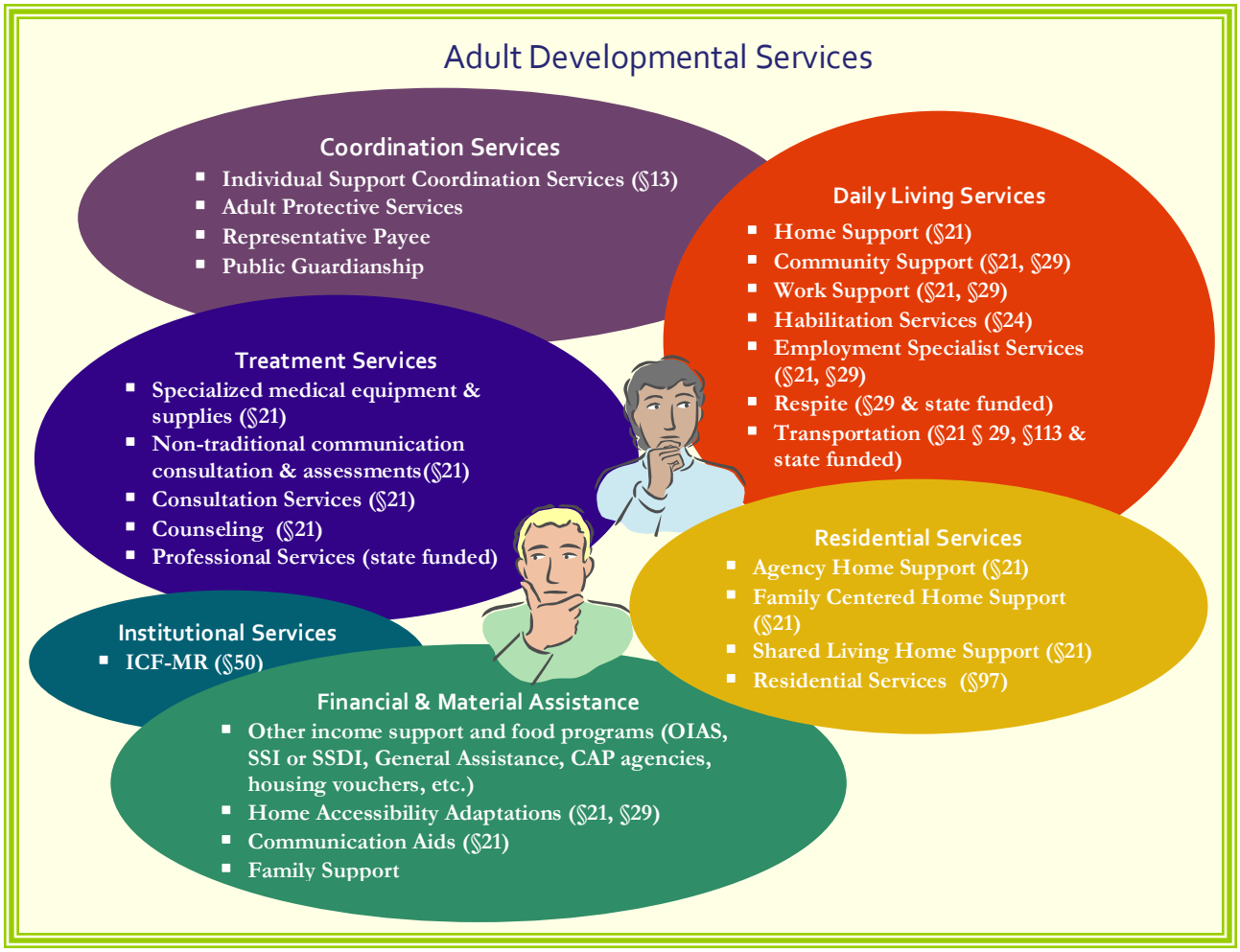
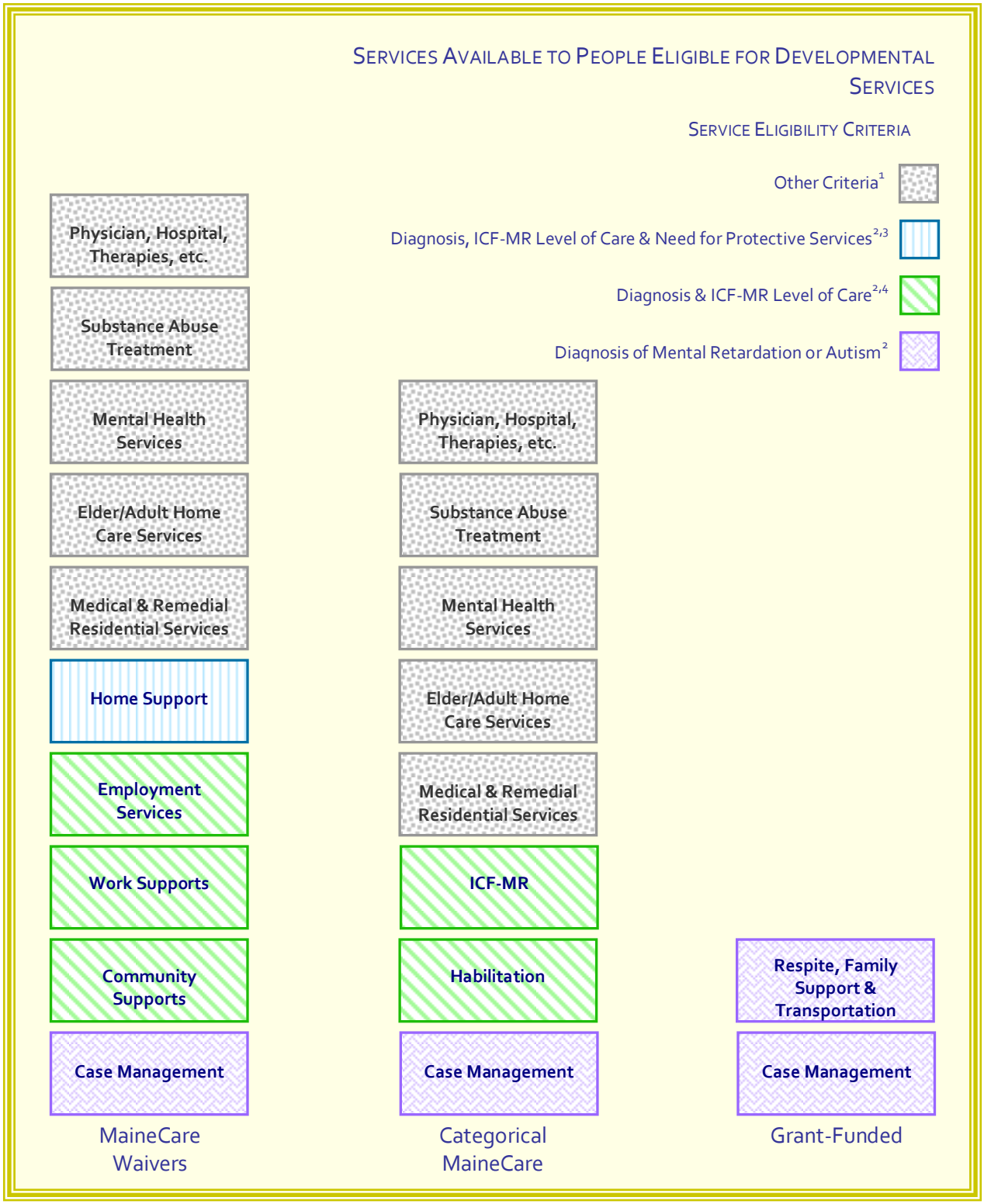
[88] Defined to include all persons who were involuntarily residents of Pineland Center at any time on or after July 3, 1975.
[89] Kimball.
[90] Supported employment definitions and guidelines, effective January 1, 2008.
[91] Executive Summary, Strengthening Communities Initiative Pilot Project: January 2004 through June 2005.
[92] 10-144 CMR Chapter 101, Chapter II, Home and Community Benefits for Members with Mental Retardation or Autistic Disorder, §21.03-2.
[93] Gallivan, Jane. Waiver memorandum, October 29, 2008. Office of Adults with Cognitive and Physical Disability Services.



Roles in the Delivery System	
Roles	*Description*
Eligible Persons	An individual meeting statutory definition of service population (*i.e.*, a person having mental retardation or autism disorder).
I&R / Outreach / Referral Sources	Schools, child case managers, family, self-referral, I&R agencies, protective services, other state agencies and DHHS offices; medical professionals. A large majority of persons entering Adult Developmental Services are transitioning from children's services and the schools.
Case Manager	Individual Support Coordinators. Both state employees working within DHHS district offices and community providers can serve as case manager.
Service Providers	Residential providers; community support providers, employment support providers, ICFs-MR, etc.
Utilization Management	DHHS determines eligibility based on a review of information and documentation gathered through intake. A case manager completes an assessment of waiver eligibility (ICF-MR level of care); a qualified mental retardation professional reviews the waiver eligibility determination. A team of senior managers within OACPDS determines whether the individual meets criteria for reserved slots.

Developmental Services	Target Population	Funding Source
Coordination Services		
Case Management. Case management can be provided by state staff or community providers. Almost all persons accessing case management services receive this service as a Medicaid service. Those not eligible may be denied or receive time limited services if resources are limited.	Adults with MR/autism	MaineCare §13 State funds
Daily Living Services		
Community Support. Direct support services predominantly provided in a community setting, to improve engagement in inclusive social and community relationships; develop skills that support health and well being. *Work Support.* Direct support services predominantly provided in a work place to improve a member's ability to independently maintain employment. *Employment Specialist Services.* Targeted employment services necessary to support a member on the job site, including periodic interventions to identify opportunities for improving productivity, minimizing the need for formal supports, adhering to work place policies, etc.	Adults needing ICF-MR level of care	MaineCare §21 & §29
Habilitation Services. Day habilitation services focus on behavior management and physical development to promote self-maintenance, physical fitness, self awareness, and to address sensory, motor and psychological needs.	Adults needing ICF-MR level of care	MaineCare §24
Respite. Temporary relief for a consumer, family or service provider.	Adults with MR/autism	State funds
Clinical Services		
Waiver. Non-traditional communication consultation & assessments; consultation services; counseling, crisis services, occupational, physical or speech therapy.	Adults needing ICF-MR level of care and requiring protective services	MaineCare §21
Professional Services. Services not reimbursable by another source, including dental services, eye examinations, and psychological examination.	Adults with MR/autism	State funds
Residential Services		
Home Support. DHHS offers a range of residential service models under the waiver.	Adults needing ICF-MR level of care and requiring protective services	MaineCare §21
Residential Services. Available under the Medicaid state plan for those that do not qualify for the waiver.	Adults with MR/autism	MaineCare §97
Hospital & Institutional Services		
ICF-MR Services. The nursing facility level provides 24 hours/day, 7 days/week nursing supervision. The group home level of care provides 24 hours/day, 7 days/week of non-nursing supervision.	Adults needing ICF-MR level of care	MaineCare §50
Financial and Material Assistance		
Family Support. Funds allocated to families to meet specifically identified needs, including respite, specialized equipment, and residential modifications.	Adults with MR/autism	State funds



[1] MaineCare services not administered by the Office of Adults with Cognitive and Physical Disabilities
[2] Services administered by the Office of Adults with Cognitive and Physical Disabilities.
[3] Eligibility criteria (ICF-MR level of care) and priority criteria (need for adult protective services) for comprehensive waiver. The need for protective services is not technically eligibility criteria although, in practice, eligibility is effectively limited to only those with a need for protective services.
[4] Eligibility criteria for the community support waiver.

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✖	Not Relevant to Population Group

Strategic Vision for a Balanced System

- **Vision statement**
  The authorizing statute for Developmental Services requires DHHS to support the establishment of community services[94] and the governing statute reflects the intent of the Community Consent Decree. Developmental Services has defined its mission in terms of its system of community services, quality of life and self-determination. This mission is widely communicated in Developmental Services' case management manual, its website and other documents available internally and externally.

- **Monitors progress toward vision**
  DHHS vision for its service system reflects many of the ideals and principles of the Community Consent Decree. As DHHS monitors compliance with the consent decree, it is effectively monitoring its progress toward achieving its visions. As part of this process, DHHS has developed definitions for this population group.

> **Office of Adults with Cognitive & Physical Disability Services Developmental Services**
>
> Mission: Developmental Services will provide leadership and be an active partner in Maine's comprehensive system of support to individuals with mental retardation and autism. At the foundation of this system is the belief that all individuals, through self-determination, can achieve a quality of life consistent with the community in which they live. Supports will be flexible and designed in a manner that recognizes people's changing needs throughout their lifetimes.

Consolidated State Agency

- **Shifting resources**
  DHHS can shift resources across ICF-MR and community budget allocations. In practical terms, doing so on a person-by-person basis is difficult – a provider with an empty bed still has fixed costs that must be met in order to provide services to other residents. However, DHHS has reallocated ICF-MR services to fund home and community based waiver services when an ICF-MR closes.

- **Coordinated policymaking**
  Office of Adults with Cognitive and Physical Disability Services (OACPDS), within DHHS, has accountability for the full range of services and supports serving adults with developmental disabilities. OAPDS is responsible for policymaking, planning and budgeting for waiver and other services available to

[94] 34-B MRSA §5003-A.

this population group, in collaboration with the Office of MaineCare Services. It also has policymaking and planning responsibility for ICFs-MR, in collaboration with the Office of MaineCare Services. OACPDS plays a less active role in shaping policy for non-waiver residential services, although it provides the seed funding for those services.

- Uses data to plan for services
  DHHS analyzes service authorization and claims data to evaluate utilization and cost. The detailed information contained in its Enterprise Information System is proving to be useful; EIS collects demographics, treatment plans, progress notes, wait list information, etc.

Single Access Points

- Information and referral
  For people eligible for case management services, information and referral is accessed through the case manager. However, there are limited low barrier options for accessing information and referral. *211 Maine* does have some information about developmental services. However, their information does not appear to be as well developed as that available through DHHS' website, which is static, submitted voluntarily by providers, and does not have the visibility of *211 Maine*. It would be useful to review this array of information and referral sources to make sure that visibility is adequate, that the assets of each are leveraged to their maximum advantage, and that access to information and referral is of consistent quality statewide.

- Linking with services
  For those who are eligible for case management services, the case manager can link the individual to a comprehensive array of services. However, for those that cannot access case management services, there is not a systematic way to link people with needed services. In general, those who are not eligible for case management services are not usually eligible for any other service through Developmental Services. However, many people transitioning to adult services who are not eligible for Developmental Services find few other resources to help them put together a plan for accessing other services. While these people fall outside of Developmental Services scope, many have a significant need for community based services and supports. DHHS might explore whether the ADRC model would be a vehicle for helping adolescents and families navigate the transition to adult services; especially for those not eligible for case management under Developmental Services.

- Coordinated community and institutional eligibility determination
  Access to community and ICF-MR services is coordinated through the person centered planning process. Developmental Services reviews the recommendation and assessment information emerging from the planning process and determines the individual's eligibility for either service.

- Coordinated clinical and financial eligibility
  The process of determining program eligibility and MaineCare eligibility is not well coordinated. If not already a member, the individual receives a referral to apply for MaineCare. For this population group, MaineCare eligibility is usually tied to an SSI disability determination. For waiver services, Developmental Services makes the level of care determination and coordinates with the financial eligibility process for MaineCare.

- Person centered planning
  Person centered planning is a statutory requirement for this population group. By statute, the person centered planning process must:

  - Be understandable and in plain language;
  - Focus on the individual's choices;

- Reflect and support the individual's goals and aspirations;
- Be developed at the individual's direction and include people whom the individual chooses;
- Be flexible enough to change as new opportunities arise;
- Be offered to the individual at least annually;
- Include all of the individual's needs and desires without respect to whether those desires are reasonably achievable or the needs are presently able to be addressed; and
- Include a provision for ensuring the individual's satisfaction with the quality of the plan and the supports that the individual receives.[95]

A person centered planning procedure guide helps to translate these requirements into standard practice, providing detailed information on the planning process and providing tools to support goal-setting and other aspects of the planning process.[96]

- Tracking waiting lists

  Both waivers establish very specific criteria for prioritizing waiting lists. Developmental Services maintains and manages a central waiting list for its comprehensive waiver.

Institutional Supply

- Privacy and autonomy considered

  Licensing standards for ICFs-MR emphasize individual privacy and offering the least restrictive level of service necessary.[97] It is not clear that these standards optimize privacy and autonomy, consistent with the needs and preferences of the people served.

- Controls on supply

  In the early years of transitioning people out of Pineland, Maine developed a number of ICFs-MR to replace the large scale institutional services. For many years now, however, Maine has been decreasing the number of people residing in an Intermediate Care Facility for Persons with Mental Retardation (ICF-MR). In recent years, DHHS has closed two state-operated ICFs-MR and recently privatized one facility serving children only.

  Maine's Certificate of Need regulations do not govern the establishment of a new ICF-MR or the increase in the number of beds. Currently, Maine has nine private ICFs-MR licensed at the group level, with a total of 52 beds; and 12 ICFs-MR licensed at the nursing level, with a total of 164 beds.[98] DHHS does effectively control the supply of ICF-MR services by limiting funding increases only to the cost of living increases required under principles of reimbursement.

Transition from Institutions

- Identifying people for transitioning

  Through the annual person centered planning process, DHHS identifies people who want to transition out of ICFs-MR. Up until it recently had to close the waiver, DHHS kept six slots open on the waiver for this purpose.

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[95] 34-B MRSA §5470-B.

[96] Maine Department of Health and Human Services, Developmental Services. 2008. Person-Centered Planning Preparation and Procedure Guide.

[97] 10-144 CMR Chapter 118, Regulations Governing the Licensing and Functioning of Intermediate Care Facilities for Persons with Mental Retardation.

[98] Obtained from a search of the Division of Licensing and Regulatory Services' Health Facilities database accessed at: https://portalxw.bisoex.state.me.us/dhhs-apps/LicCert/pgDetails.asp on February 7, 2009.

- **Funds transition planning**
  State-funded case management services support transition planning for people in ICFs-MR.

- **Funding for one-time transition expenses**
  Family funds can be used to pay for home modifications and other services that support family unity. It is unusual for people in this population group to transition from an ICF-MR to a personal home or apartment, so many of the one-time costs associated with transition do not apply.

Continuum of Residential Options

- **Privacy and autonomy considered**
  Residential services are licensed as required (group settings of three or more people living together) under the Assisted Housing regulations, described in the OLDER ADULTS AND ADULTS WITH DISABILITIES section, and articulate an individual's right to privacy and the right to choose his or her activities. The regulations require residential providers to solicit residents' preferences when planning activities and to encourage residents to participate in meal planning and to use their own furnishings in their rooms. The licensing regulations however do not place a heavy emphasis on privacy and control and do not require staff to be trained in person centered care or services.

- **Range of options**
  A range of residential options are available under the waiver:

  Supported living. Home supports are provided in the individual's own home, on less than a 24 hour/day basis.

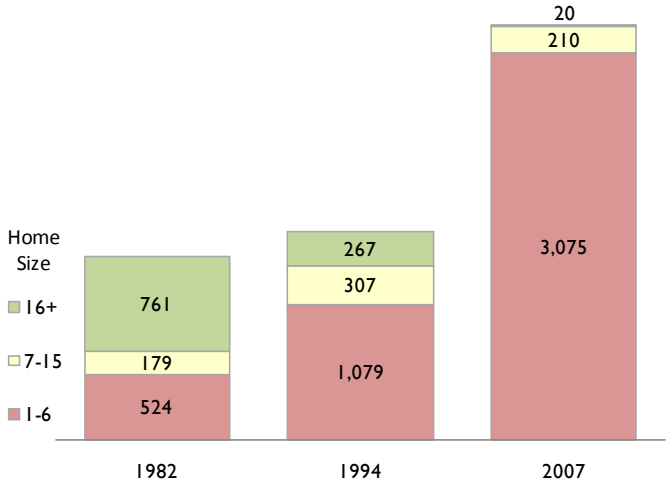
  Shared living. A housemate, under contract with a provider agency, provides direct support services in a home owned by the housemate or the individual being served.

  Family centered support. Provides enhanced home support to a member in a family environment, with the family and the member sharing a home that is not owned by the member or member's family. This model is being phased out.

  Group living. Agency-based residential services serve small groups, usually up to four to six people.

  In addition, MaineCare non-waiver residential services are also available.

Maine Persons with Developmental Disabilities by Home Size 1982, 1994 and 2007



Source: Prouty, Robert W., et al. 2008. Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007, p. 119. Research and Training Center on Community Living, University of Minnesota.

- **Up-to-date information about available options**
  DHHS provides information on community providers, including residential providers on its website. The website includes contact information and self-reported information about the nature of the services provided, etc. The information is submitted by the provider and can vary in quality and level of detail. However, it provides more detailed and accessible information than can be obtained through *211 Maine*. These residential options could be kept up to date and be more visible if included in the housing registry currently under development by DHHS and MSHA.

Long Term Services and Supports Infrastructure Development

- ● Case management
  Case management services are available for this population group. The caseload is capped at a 35:1 ratio.

- ◉ Develops workforce to meet needs
  DHHS has established training programs and manuals for key components of the workforce serving this population group. DHHS has developed training curricula for its case managers and direct support professionals. The DSP curricula is a competency based curricula that addresses client rights, choice, community inclusion, etc. The case management manual sets standards for case management services and procedures.

  DHHS reports that it has anecdotal information about workforce shortages but is not able to confirm with data. Staff believe that the rate structure for this population group, which reimburses based on wages and benefits, reduces some of the problems experienced in other programs.

- ◉ Support for informal caregivers
  The Community Support waiver assumes that people receiving services under the waiver are receiving informal supports. The Community Support waiver covers respite services for those providing informal support services; however, DHHS is revisiting its provider qualifications before those services are made available under the waiver. State-funding is also available for respite services and other supports that help to maintain the family unit, including specialized equipment and residential modifications; these funds have become more limited with budget cuts.

- ○ Uses evidence based practices
  DHHS does not have a formal process for considering and incorporating evidence-based practice into their policy and practice, although is an area of interest going forward.

- ● Stakeholders participate in planning for services
  DHHS provides support to Speaking Up for Us (SUFU), a self-advocacy group supporting persons with developmental disabilities. DHHS invites SUFU members to inform policymaking by providing feedback on policy changes or assisting in the development of tools and resources. For example, SUFU members helped to develop a series of tools for educating people about consumer direction. DHHS has also worked with consumers on a community inclusion pilot. The participating consumers helped clarify the definition of "inclusion" for providers participating in the pilot.[99] Through legislative and other initiatives DHHS works with other stakeholders to develop policy, identify service gaps, and implement new programs.[100] DHHS consulted with consumers and providers in developing and implementing standardized rates for waiver services. DHHS also regularly works with the Disability Rights Center, a legal advocacy group.

Consumer Direction

- ◉ Individualized budget
  DHHS has started to build the infrastructure necessary to implement consumer directed services. Under a 2003 Money Follows the Person grant, Maine developed a published rate structure, providing the foundation for developing individualized, portable budgets. It is currently exploring its options for incorporating a budget allocation tool into its service planning process.

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[99] Executive Summary, Strengthening Communities Initiative Pilot Project: January 2004 through June 2005.
[100] See, for example, The Governor's Working Group on Mental Retardation Services. 2005. Final Report of the Working Group.

- ◉ Option to hire own workers
  DHHS does not offer a consumer-directed option allowing consumers to hire their own workers. Under a 2003 Independence Plus grant DHHS also developed a waiver application and tools for implementing a self-directed waiver. However, funding for the self-directed waiver was not available when it came time to implement. DHHS is considering making consumer direction an option under its Community Support waiver.

- ○ Option to purchase goods and services
  DHHS does not offer consumers the option to purchase goods and services outside the standard service package.

Quality Management

- ◉ Quality management plan
  The Quality Improvement/Quality Assurance system for OACPDS provides ongoing review of activities – ensuring health and safety, achieving individual needs met, measuring people's involvement in their communities and monitoring the many requirements which govern DHHS' delivery of services.

  The Community Consent Decree also sets standards for DHHS' system of community services for adults with developmental disabilities.

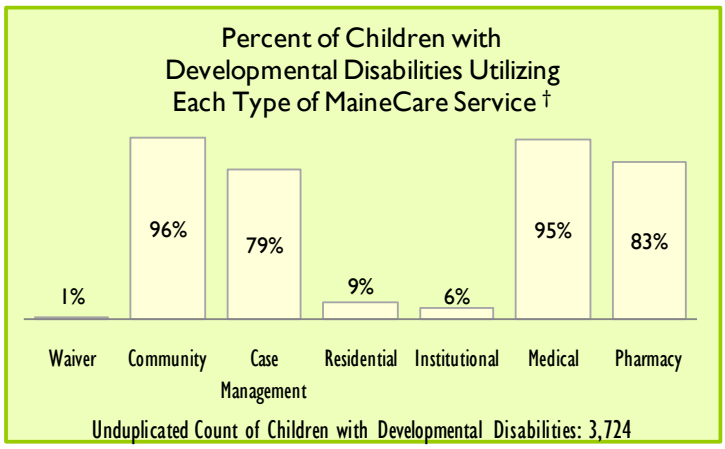
- ◉ Quality measurement
  The Office of Quality Improvement participates in the National Core Indicators Project to establish common data and outcome indicators for assessing service quality for adults with cognitive and developmental disabilities. This is a joint project with the Office of Adults with Cognitive and Developmental Disability Services.

- ◉ Consumer surveys
  The National Core Indicators Project includes measures of consumer satisfaction in both its consumer and family survey tools.

Children

Children with Developmental Disabilities

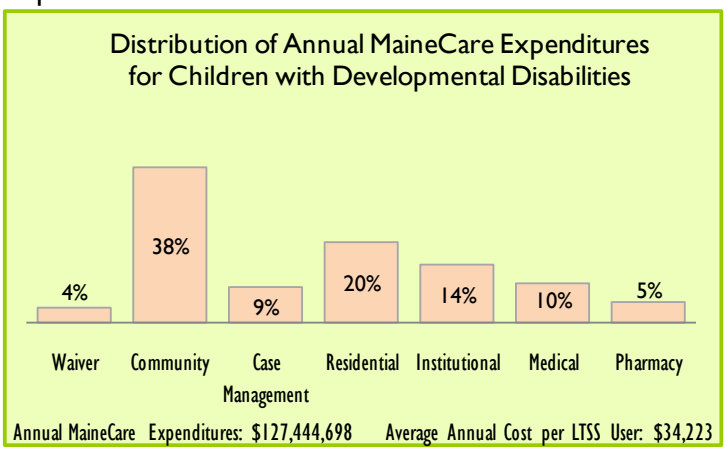
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- 96% of children with developmental disabilities accessed services in the community.
- 9% accessed residential services and 6% accessed ICFs-MR or other institutions.
- 95% accessed medical services.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- Expenditures for community services are the major component of costs for this group (38%).
- Although small numbers of children are in residential or institutional care, the expenditures for institutional and residential services represent approximately one-third of total costs (34%).

DEFINITIONS AND DATA

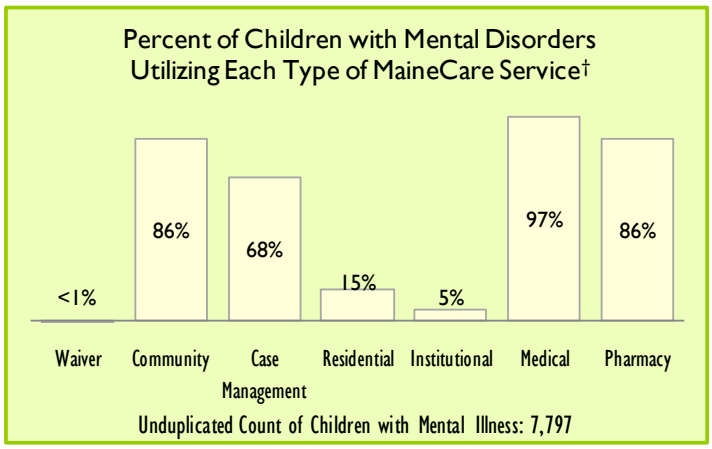
Children with Developmental Disabilities were defined as members age 17 or under at the beginning of the year who were receiving day habilitation services or had a mental retardation diagnosis.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. LTSS children were identified based on a hierarchy 1.) with developmental disabilities; 2.) with mental disorders and 3.) with physical disabilities; children are placed in only one group.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

Children with Mental Disorders

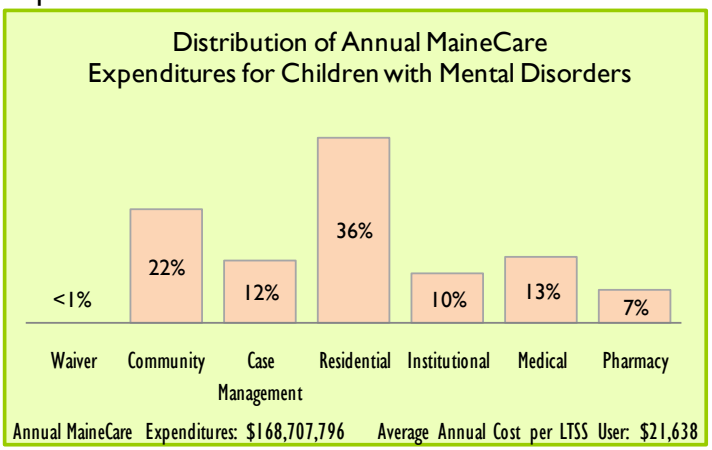
Utilization



†The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- Approximately 7800 children were identified as having mental disorders. 86% accessed services in the community.
- 20% accessed residential or institutional services.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- Residential and institutional services represent 46% of total costs for this group.
- Community services represent 22% of the total costs.

DEFINITIONS AND DATA

Children with Mental Disorders were defined as members age 17 or under at the beginning of the year who accessed specific mental health services (targeted case management, residential treatment, behavioral health services); or had two or more inpatient psychiatric or crisis stabilization unit stays in the year.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. LTSS children were identified based on a hierarchy 1.) with developmental disabilities; 2.) with mental disorders and 3.) with physical disabilities; children are placed in only one group.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

System Strengths

Commitment to Community. Children are predominantly served in the community. DHHS manages utilization of residential treatment services and admission to Maine's one ICF-MR serving children is subject to judicial review.

Family Centered Services. DHHS uses a wraparound planning model that is highly individualized and strengths-based. It is currently working to enhance this planning model.

Coordination and Collaboration. The merger of children's behavioral health and child welfare services has helped to create better alignment of policy and practice across those programs.

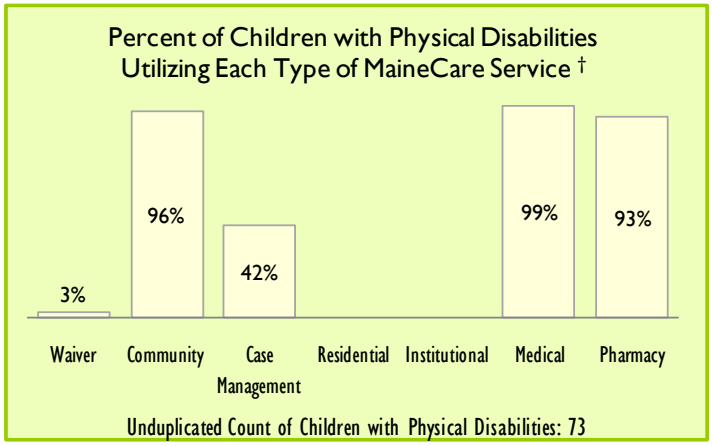
Evidence-Based Practice. DHHS' contracted providers have implemented a number of evidence-based practices and best practices.

Areas for Further Examination

Consumer Direction. Consistent with its individualized and strengths-based planning model, DHHS might explore the feasibility of applying a consumer directed model to in-home habilitation services, and other services, allowing families the option to select and manage their own service providers.

Children with Physical Disabilities

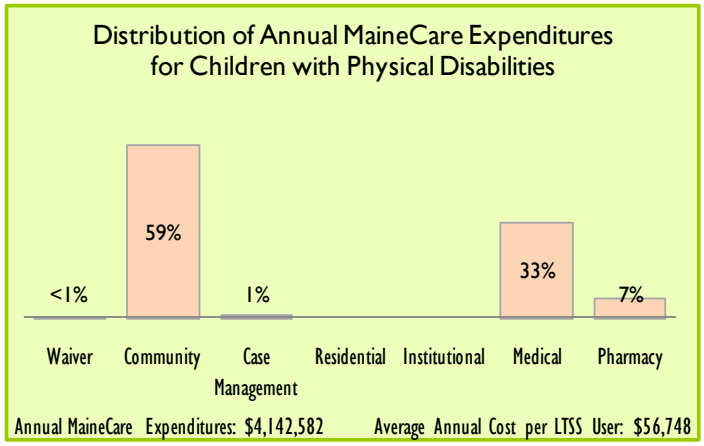
Utilization



† The percent of LTSS users adds up to well over 100%, because nearly all LTSS accessed more than one type of MaineCare service during the year.

- Only 73 people were identified in this group of children.
- 96% of the children in this group accessed community services.
- 42% accessed case management services.
- Almost all the children used medical or pharmacy services.

Expenditures



†Percent of expenditures add to 100% because each MaineCare dollar was attributed to a single service category.

- 33% the expenditures for children in this group were for medical expenses.

DEFINITIONS AND DATA

Children with Physical Disabilities were defined as members age 17 or under at the beginning of the year who accessed private duty nursing program.

Data Source: MaineCare claims data from the MMDSS extract housed at Muskie and updated as of 2/28/2009. Claims incurred between 7/1/2007-6/30/2009 based on from service date and paid as of 2/28/2009. Hospital payments are estimates based on DHHS established algorithm. Claims payments do not reflect any adjustments, rebates, settlements or other off claim transactions. LTSS members were defined using claims service use and diagnostic data. These grouping are preliminary and will be refined in year two of this study. LTSS children were identified based on a hierarchy 1.) with developmental disabilities; 2.) with mental disorders and 3.) with physical disabilities; children are placed in only one group.

See PROCESS AND APPROACH for more detail on how populations and service categories are defined.

System Strengths

Community-Based Services. Children with physical disabilities are served in the community, and do not access residential or institutional service.

Areas for Further Examination

Policy "Ownership." While small in numbers, DHHS might consider assigning policymaking "ownership" for this group, to ensure that they have access to cost-effective services that best meet the needs of children.

Access to Case Management. While some children in this group were able to access case management or care management services under other programs, it's not clear that all who could benefit from case management have access to it.

Children

This section describes services for all children served by DHHS who potentially having a long term need for services. These children primarily fall into two groups:

Children with Behavioral Health Needs

For children with behavioral health needs, DHHS defines three target populations:

- Children, age birth through 5, who have developmental disabilities or severe developmental delay, or are at risk of cognitive or mental impairment, or emotional or behavioral disorder;
- Children and adolescents, age 0-20, who have emotional or behavioral needs including children with serious emotional disturbance; and
- Children, age 0-20, who have mental retardation, autism or pervasive developmental delay.

Children with a mental health diagnosis might have an anxiety disorder, a mood disorder (*e.g.*, depression), attention deficit and disruptive behavior disorders, schizophrenia, and other mental disorders. Among this group, is a subset – children with symptoms of significant severity that the criteria for having a serious emotional disturbance is met. For these children, their mental disorder disrupts their daily functioning in their home, school and community. A pervasive developmental disability (PDD) includes a spectrum of disorders including Autistic Disorder, Asperger's, Rett's Disorder and other conditions. PDD affects the way a person comprehends, communicates and relates to others. Mental retardation affects a child's development, impacting the ability to communicate and learn the skills of daily living. Most children with mental retardation are classified as "mild" and can learn to live relatively independently, with the right supports.

Children with Physical Disabilities

This population group is defined by a long term need for nursing or other medical care, or a need for assistance with activities of daily living. Children with a physical disability might have muscular dystrophy, spina bifida, cerebral palsy, or another condition causing their impairment or they might have acquired the disability from an injury. Children in this population group may need access to therapies, including occupational therapy or speech. They also may need access to specialists and special equipment.

Like the adult populations, the children served by DHHS can fall into multiple groups. For example, a child with a developmental disability might also have a physical disability or a mental illness; a child with a mental illness might also have a substance abuse problem. In addition, the needs of family members can also play a significant role in the care and well-being of children. And children's services can cross multiple systems. In addition to the health and mental health systems, a child might be involved in a school system, the child welfare system, and juvenile justice. Thus, for children, the need for integrated and coordinated services becomes all the more important, at both the policy level and at the practice level, where children and families interact with these systems.

Programs and Services

Children with Behavioral Health Needs

For children with behavioral health needs, the program of services has gradually evolved through various stages of organizational integration and alignment, and changes in the standard of practice and population served. Concurrent with Maine's de-institutionalization period, a patchwork of programs emerged to serve children. In 1985 the Bureau of Children with Special Needs (BCSN) was created and eventually became the umbrella agency for programs serving children with special needs including several grant funded programs. BCSN became the

unified administrator for the Autism Project serving children birth – 20; early intervention services (birth -5); and services for school-age children with mental retardation transferred from the Bureau of Mental Retardation. Maine was one of the first ten states awarded a federal Child & Adolescent Service System Program (CASSP) grant that promoted cross-system collaboration on behalf of children with severe emotional disturbance.

In 1997, the Legislature required the legacy children's mental health agency to design a comprehensive system of services for children with mental health needs, with the consultation of the Departments of Human Services, Corrections and Education.[101] Based on the resulting 1998 report, the Legislature established the Children's Mental Health Program, which continues today. By statute, DHHS is responsible for developing a coordinated system of services for children, including a comprehensive system of family supports with an emphasis on local administration.[102] When possible, services are to be in-home, community-based and family-oriented; when out-of-home services are necessary, they are to be provided in the least restrictive appropriate setting.

At the time of this initiative, there were a number of drivers for reform. Growing attention was being paid to the number of children served in out-of-state placements. In 1997, 75% of Medicaid expenditures were spent on the most restrictive and costly services for children, including residential treatment and psychiatric hospitalization. [103] In 1998, Maine was serving approximately 260 children out of state.[104] Children served in out-of-state hospitals had an average length of stay four times as long as those hospitalized in state, and the cost per child was more than three times greater.[105]

At the same time, parents and advocates were frustrated with long waiting lists for children's services. In 1997, in *French v. Concannon*, advocates used Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirement to successfully challenge long waiting lists for case management and home and community based services. As a result of *French*, the case management function was transitioned from case managers employed by the State to contracted community providers. *Risinger v. Concannon*, another class action suit, followed up on *French*. Settled in 2002, in *Risinger* the State agreed to comply with wait time standards for case management services and in-home support services.

Also in 2002, a series of newspaper articles highlighted the ongoing challenges of finding services for children in Maine. Appearing during an election year, these articles generated a campaign promise to merge children's services into one department. The new governor followed through on that promise by creating the new Department of Health and Human Services in 2004. Within DHHS, the new Office of Child and Family Services (OCFS) brought together Children's Behavioral Health Services, Child Welfare and Early Childhood Services.

Office of Child and Family Services
Children's Behavioral Health Services

Mission: To provide leadership in the development of a comprehensive system of care that ensures that each child develops to their fullest capacity. The system of care strengthens the capacity of families, promotes natural helping networks, and develops community resources to meet the behavioral, developmental, and treatment needs of children.

Guiding Principles

- Services should be based on the family's and child's strengths.
- Families and youth should be full participants in all aspects of planning and delivery of services.
- Children should receive services in the least restrictive, most normative environment that is clinically possible.
- Focus is to build and foster natural and community-based supports with each family.

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[101] P.L. 1997, Chapter 80, *Resolve, to Plan for Services for Children with Mental Health Needs.*
[102] 34-B MRSA §6203(1).
[103] Department of Mental Health, Mental Retardation and Substance Abuse Services, et al. 1997. *A Plan for Children's Mental Health Services.*
[104] Maine Department of Health and Human Services, Children's Behavioral Health Services. 2005. *Performance Partnerships Block Grant: Application and Plan Fiscal Year 2005.*
[105] Maine Department of Mental Health, Mental Retardation and Substance Abuse Services, et al. *A Plan for Children's Mental Health Services.*

This period of reform has had a meaningful impact on where children are served. In 2008, the number of children served by Children's Behavioral Health Services in out-of-state placements totaled 17, a 93% reduction since 1999.[106] Today, DHHS has no waiting lists for these services and has been formally in compliance with the *Risinger* settlement agreement since September, 2007. The agreement will be dismissed in September, 2009.

Since the merger, OCFS has also improved the integration of child behavioral health and child welfare. Co-location, improved information sharing and coordinated policy development has helped to create greater alignment of policy and practice; OCFS has recently implemented a policy for a single case manager when a child is served by both agencies. OCFS has also redesigned residential treatment services to serve children on a short-term basis, for treatment only. Access to residential treatment for both children's behavioral health, and now child welfare services, is managed through DHHS mental health coordinators and utilization review. Currently, the average length of stay in a residential treatment facility is 189 days.[107]

Children with Physical Disabilities

There is no program with responsibility for overseeing the long term supports and services for children with physical disabilities. The Office of Elder Services plays the largest role in shaping MaineCare funded long term supports and services for this population, largely by shaping policy for older adults and adults with disabilities. Otherwise, the Office of MaineCare Services is responsible for setting policy for the MaineCare-funded services available to this population group. The Office of MaineCare Services also manages the eligibility determination process for nursing facility of care for children applying under the "Katie Beckett" option, discussed below. The Children with Special Health Care Needs Program is housed within the Centers for Disease Control and administers Maternal and Child Health Program funds. This program provides care coordination and pays for diagnostic evaluation, medication, specialists, hospitalization, surgery and other items for children meeting eligibility guidelines. Due to budget constraints, this program closed enrollment as of March 2008.

Services

The picture on the next page shows the array of services available to children needing long term supports and services. These services are described in the grids on pages 114-115.

Clinical Eligibility

Clinical eligibility criteria include diagnosis and functional criteria, depending on the service. Below is a simplified summary of the eligibility criteria applied.

Case Management: To be eligible for case management services, a child or adolescent must be:

- Age birth through 5, who have developmental disabilities or severe developmental delay, or are at risk of cognitive or mental impairment, or emotional or behavioral disorder;
- Age 0-20, who have emotional or behavioral needs including children with serious emotional disturbance;
- Age 0-20, who have mental retardation, autism or pervasive developmental delay.

For a mental health diagnosis, DHHS uses DSM-IV Axis I diagnosis and for children age 0-5, the DC: 0-3 Diagnostic Classification of Mental Health Developmental Disabilities of Infancy and Early Childhood may be used. DSM-IV Axis II is used for a mental retardation diagnosis.

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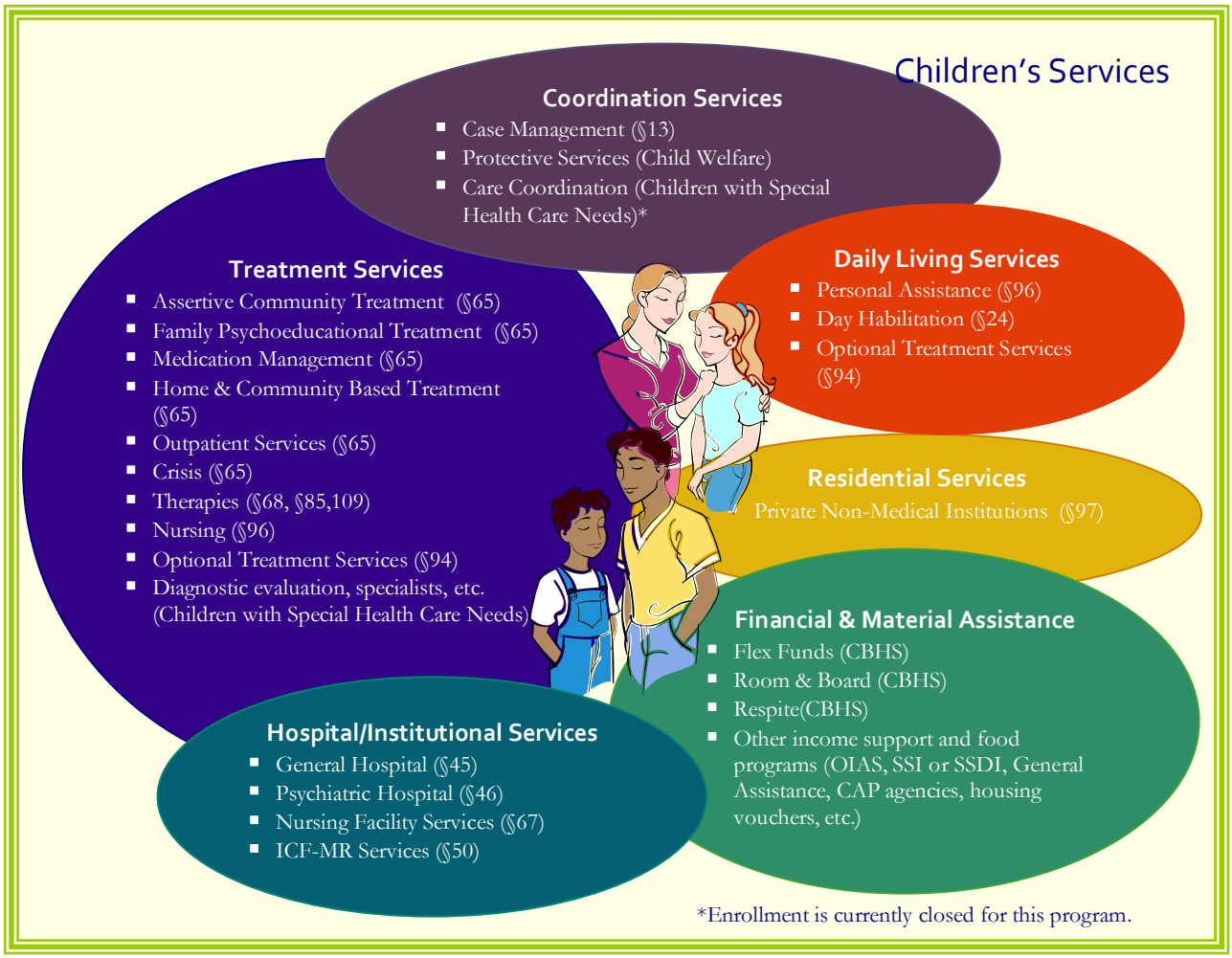
[106] Maine Department of Health and Human Services. 2009. *In Focus Reference Book*.
[107] O'Brien, Ann, Office of Child and Family Services, Maine Department of Health and Human Services. Email communication, March 9, 2009.



Mental Health Services. For children's mental health services, DHHS uses several layers of clinical eligibility criteria for targeting mental health services for children. Simplified, these layers include:

Mental Disorder. A diagnosis of a mental disorder is the threshold for accessing outpatient treatment, crisis services; home and community based treatment, medication management, ACT and family psychoeducational services.

Serious Emotional Disturbance. In accordance with state law, Maine defines serious emotional disturbance in terms of the federal definition. A child has serious emotional disturbance (SED) if he or she has a mental health, emotional, or behavioral diagnosis that has lasted for at least a year and has resulted in a functional impairment which substantially interferes with or limits the child's ability to function in family, school, or community activities. The more intensive mental health services (home and community based treatment, ACT services, and family psychoeducational services) are reserved for children with a diagnosis of SED. In addition to a diagnosis or functional impairment, eligibility for some services is conditioned on the risk that, without the service, the child would require a higher level of care. For example, ACT services are available to those children who would be at risk of hospitalization without them.

Developmental Services

Need ICF-MR Level of Care. In addition to a diagnosis of mental retardation or autism, access to habilitation services or ICF-MR services is based on whether the child has a need for an institutional level of service.

Services for Persons with Physical Disabilities

Need for Nursing Services or Personal Assistance. As for adult services, access to home-based nursing and personal assistance and nursing facility services is conditioned on the need for assistance with activities of daily living (ADLs), including eating, bathing, dressing, mobility, locomotion, etc., and nursing services.

Children with Special Health Care Needs (CSHCN). This program is available to children with a medical condition that restricts functioning or causes developmental delays; requires a level of health care beyond routine basic care; requires pediatric subspecialty care and can be maintained or improved by the treatment; and has one of the congenital or acquired chronic diseases, conditions, or physical disabilities identified.[108]

Other Services

Optional Services. Under federal Medicaid law, children may access optional treatment services when they are medically necessary to address illnesses and conditions identified through Early and Periodic Screening, Diagnosis and Treatment Services (EPSDT).[109] A child not eligible for a service based on program rules may still be eligible for the services if it is medically necessary and meets other criteria specified by rule.

Early Intervention Services. Early Intervention Services provide group infant/toddler services, integrated support for preschool children and support for families of children 0-5. These are state-funded services.

Financial Eligibility

MaineCare Eligibility. Children age 0 to 18 in families with income less than 200% of the Federal Poverty Level qualify for MaineCare. DHHS also uses a "Katie Beckett" eligibility option, considering only the income and assets of the child, if the child has a disability meeting SSI criteria and requires institutional level of care but is residing in the community. Depending on the family's income, they may have to pay a monthly premium.

Sliding Fee Scale for State-funded Services. DHHS applies a sliding fee scale to several state-funded programs (case management, respite and outpatient services) with no fee charged up to 250% of the Federal Poverty Level.

Children with Special Health Care Needs (CSHCN). There are no financial eligibility criteria for accessing care coordination services. Financial eligibility for subspecialty care and other services is limited to those with incomes below 225% of federal poverty guidelines.[110]

Delivery System

Children needing long term supports and services may be identified at birth, through pediatric visits, or in school. ChildFind, the early identification and early intervention program administered by the Department of Education also links children into the service system. (Child Find is a federally mandated program established under the Individuals with Disabilities Education Act, IDEA, the federal special education legislation.)

Waiting Lists

Children's Behavioral Health Services monitors wait times for case management, day habilitation services and home and community based treatment services. All wait times are under the federal standard of 180 days. There is no waiting list for private duty nursing and personal care services for children with physical disabilities. Children with Special Health Care Needs Program closed enrollment as of March 2008.

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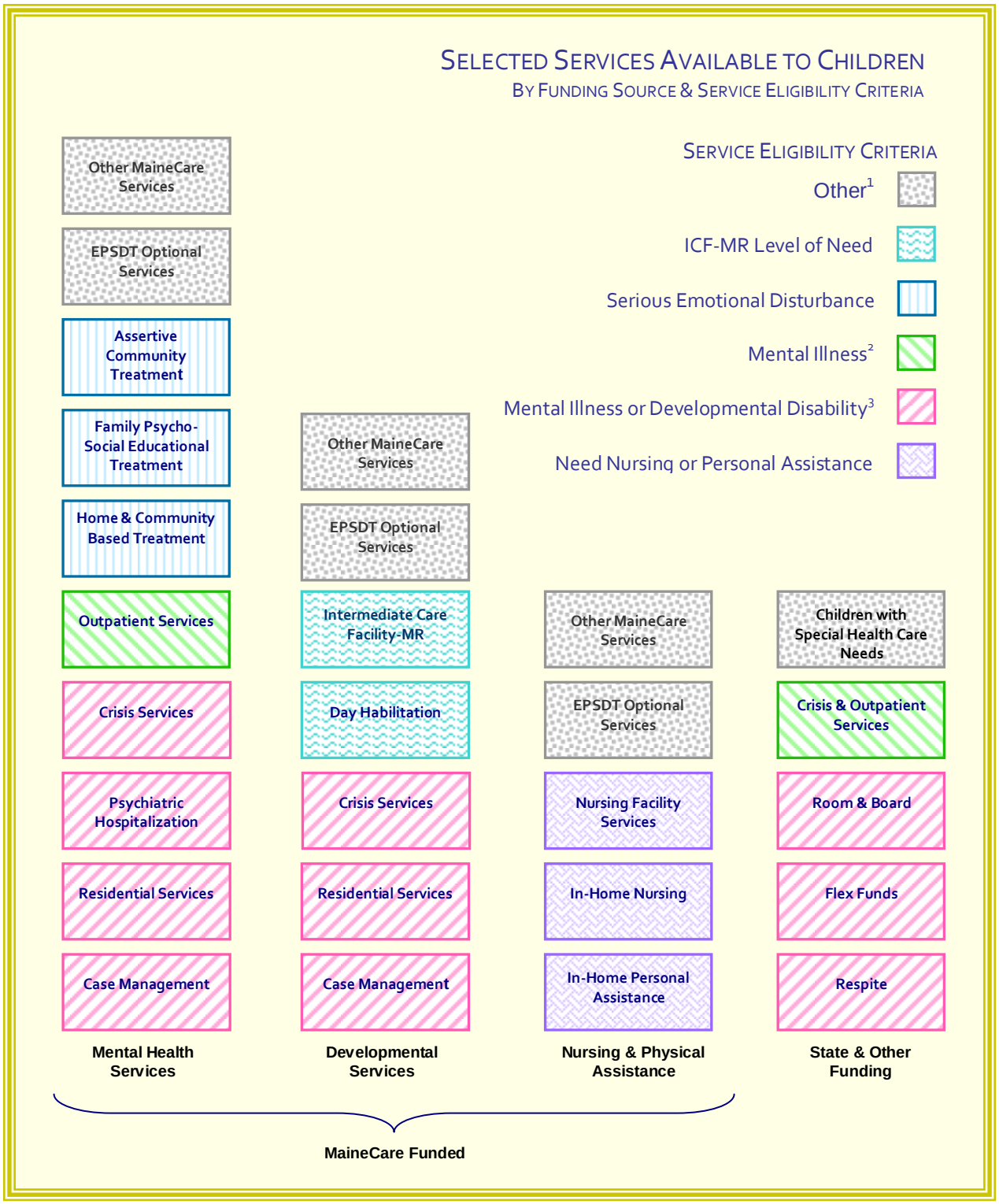
[108] 10-144 CMR Chapter 272, Coordinated Health Services For Children with Special Health Needs.
[109] 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, §94.
[110] 10-144 CMR Chapter 272, Coordinated Health Services For Children with Special Health Needs.

Children's Services	Target Population	Funding Source
Coordination Services		
Case Management. Provided by community case managers who help identify and locate appropriate treatment services. Two levels of case management services are provided depending on the degree of service intensity required. Level I focuses on resource coordination and Level II provides intensive case management for those with extensive needs.	Children and youth with a mental disorder, a developmental disability or, for children age 0-5, are at-risk for a cognitive, mental or behavioral disorder	MaineCare §13
Coordinated Care Services for Children with Special Health Care Needs. Care coordination for medical care, rehabilitative and other services.	Children with physical, developmental or medical condition	Federal funds (Maternal & Child Health Program)
Daily Living Services		
Day habilitation services. Focus on behavior management and physical development to promote self-maintenance, physical fitness, self awareness, and to address sensory, motor and psychological needs.	Children needing ICF-MR level of care	MaineCare §24
Respite. Temporary, planned relief for parents or caregivers for children with serious emotional disturbance or developmental disabilities.	Children with mental disorder or develop. disability	State Funds
Personal Assistance. In-home personal assistance.	Children needing personal assistance services	MaineCare §96
Treatment Services		
Outpatient Services. Outpatient services are professional assessment, counseling and therapeutic services designed to relieve the child's symptoms, promote positive growth and offer ways to improve or stabilize the child's family living environment and minimize the necessity for out-of-home placement. *Medication Management.* Prescribing, administering and monitoring medication.	Children with mental disorder	MaineCare §65
Crisis. Crisis services are individualized therapeutic services available 24-hours a day, 7 days a week to children that are experiencing a psychiatric emergency. The services can be provided in a child's home, school, a shelter, or another setting.	Children with mental disorder or develop. disability	MaineCare §65
Home and Community Based Treatment. Home and community based treatment includes therapy, counseling or problem-solving activities to help the child develop and maintain skills and abilities necessary to manage his or her mental health treatment needs, learn the social skills and behaviors necessary to live with and interact with the community members and independently, and to build or maintain satisfactory relationships with peers or adults.	Children with serious emotional disturbance	MaineCare §65

Children's Services	Target Population	Funding Source
Treatment Services, continued		
Assertive Community Treatment. Children's Assertive Community Treatment (ACT) service is an intensive 24-hour, 7 days a week service provided in the home, school and community to prevent psychiatric hospitalization or admission to a residential treatment facility.	Children with serious emotional disturbance	MaineCare §65
Private Duty Nursing. In-home nursing services.	Children needing nursing services	MaineCare §96
Coordinated Care Services for Children with Special Health Care Needs. Subspecialty treatment, surgery or related expenses for congenital or acquired disorders that require long-term subspecialty physician treatment and have a good prognosis for cure or improved functioning.	Children with physical, developmental or medical condition	Federal funds (Maternal & Child Health Program)
Residential Services		
Residential Services. Intensive Temporary Residential Treatment Services are residential services for children with mental retardation, autism, severe mental illness, or emotional disorders, who require 24-hour supervision. ITRT is provided in the least restrictive environment possible, with the goal of placement as close to the child's home as possible. The purposes of ITRT is to provide all services to both treat the mental illness or disorder and to return the child to his or her family, home and community as soon as possible.	Children with serious emotional disturbance	MaineCare §97
Hospital & Institutional Services		
Hospital Services. Psychiatric hospitalization is available through two psychiatric hospitals (Spring Harbor and Acadia) or through two community hospitals (St. Mary's and Northern Maine Medical Center). Children are not admitted to Maine's state-operated facilities. Psychiatric hospitalization is not available as a long-term placement.	Children with mental disorder	MaineCare §45 & §46
ICF-MR Services. Maine has one ICF-MR for children, providing nursing facility level of care. Nursing supervision and a coordinated program of health treatment and rehabilitative services are available 24 hours, 7 days a week.	Children needing ICF-MR level of care	MaineCare §50
Nursing Facility Services. Facility-based nursing and personal care assistance.	Children requiring nursing facility level of care	MaineCare §67
Financial and Material Assistance		
Flex Funds. Short term services addressing a need identified in the child's individual service plan, when no other funding source is available.	Children with a mental disorder or develop. disability	State funds
Room & Board. Non-treatment costs associated with residential services.	Children with mental disorder or develop. disability	State funds
Wraparound Funds. Wraparound funds support children who are involved with a minimum of three child serving systems, who have intense needs and the child's or family's needs cannot be met with other funding sources.	Children with mental disorder or develop. Disability	State funds



[1] Medical necessity, specific diagnoses, or other program criteria.
[2] Includes children age 5-20 with DSM Axis I diagnosis or children age 0-5 with a diagnostic classification 0-3 for Diagnostic Classification of Mental Health Developmental Disabilities of Infancy and Early Childhood.
[3] Includes children age 5-20 with DSM Axis I diagnosis or children age 0-5 with a diagnostic classification 0-3 for Diagnostic Classification of Mental Health Developmental Disabilities of Infancy and Early Childhood; children age 0-5 at risk of mental, emotional or behavioral impairment; and children age 0-20 with DSM Axis 2 diagnosis.

Roles in the Delivery System	
Involved Entity	*Description*
Eligible Persons	*Children with Behavioral Health Needs.* Includes children, age 0-5, who have developmental disabilities or severe developmental delay, or are at risk of cognitive or mental impairment, or emotional or behavioral disorder; children and adolescents, age 0-20, who have emotional or behavioral needs including children with serious emotional disturbance; children, age 0-20, who have mental retardation, autism or pervasive developmental delay. *Children with Physical Disabilities.* Includes children who need assistance with activities of daily living and nursing services.
I&R / Outreach / Referral Sources	*Children with Behavioral Health Needs.* Three Family Information Specialists employed by Children's Behavioral Health Services provide information and facilitate access to services; five family parent organizations provide information and referral, each with particular focus or service need. Pediatricians, the developmental evaluation clinics funded by the Maine Center for Disease Control, and the Department of Education's Child Development Services are sources of referrals into the system. *Children with Physical Disabilities.* The same sources of referrals apply for this group of children.
Case Manager	*Children with Behavioral Health Needs.* All case management services are delivered by community providers. *Children with Physical Disabilities.* Service coordination for long term supports and services is not available for this population group. Care coordination for treatment services is available to children meeting the eligibility criteria for Children with Special Health Care Needs program (having a congenital or acquired chronic disease, condition or physical disability). Enrollment in this program has been closed since March 2008.
Service Providers	*Children with Behavioral Health Needs* ▪ Mental health case management providers ▪ Mental retardation case management providers ▪ Day habilitation providers ▪ Mental health treatment agencies ▪ Residential treatment providers ▪ ICF-MR (Maine has only one ICF-MR serving children) ▪ Psychiatric hospitals *Children with Physical Disabilities* ▪ Home health agencies ▪ Nursing facilities ▪ Surgical, pediatric and rehabilitative specialists
Utilization Management	*Children with Behavioral Health Needs* Access to in-home behavioral health treatment and Assertive Community Treatment require prior authorization by an administrative service organization (ASO). The ASO does not review the initial provider determination of eligibility for other services, but does approved continued care for case management, hospital services, outpatient services, residential services or crisis services. Access to residential treatment and out-of-state services is authorized by Children's Behavioral Health Services' mental health coordinators and utilization review staff. *Children with Physical Disabilities* DHHS' care management consultant reviews utilization for children accessing in-home nursing and personal care services.

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is-s meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✖	Not Relevant to Population Group

The systems serving children with behavioral disabilities are distinct from those serving children with physical disabilities. The analysis of the system components is done separately for each.

Children with Behavioral Disabilities

Strategic Vision for Rebalancing

● Vision statement

Children's Behavioral Health Services defines its vision for the children it serves as "All children will thrive in their home and community and live healthy, safe and happy lives." This vision is reinforced by statute, which requires DHHS' children's mental health program to be "child and family-centered, focusing on the strengths and needs of the child and the child's family" and to provide an individualized treatment planning process that includes the participation of the family.[111] Services must be provided as close to the child's residence as possible. The statute requires DHHS to shift block grant funding to community services.

● Monitors progress toward vision

DHHS monitors outs-of-state placements, utilization of residential treatment services, and provider contracts to monitor progress toward its vision. As part of this process, DHHS has developed definitions for children requiring long term supports who have a serious emotional disturbance or developmental disabilities.

Consolidated State Agency

◉ Shifting Resources

DHHS as a whole has budget authority over hospital level, residential care and community-based services for children. Within these areas, OCFS has budget authority for habilitation services, but not ICF-MR services for children. OCFS does not have authority to shift resources from hospital level or residential care to home and community-based services.

◉ Coordinated policymaking

Children's Behavioral Health Services is responsible for planning, budgeting and policymaking for Children's Behavioral Health Services including residential and community and home-based services. It does not coordinate planning, budgeting and policymaking for ICF-MR services, although DHHS as a whole is accountable for budgeting across the spectrum of care.

[111] 34-B MRSA §15002.

- Uses data to plan for services

  DHHS does use data to plan for services. For example, Children's Behavioral Health Services conducted a major system redesign based on the evaluation of two mental health services that showed poor outcomes. As a result intensive mental health home and community treatment service was developed replacing these two services; the Child and Adolescent Functional Assessment Scale (CAFAS) was instituted for prior authorization and utilization review for this treatment service.

Single Access Points

- Information and referral

  Information and referral is provided by five statewide family organizations, two county organizations and three Children's Behavioral Health Services family information specialists. The statewide family organizations have a focus area that allows them to provide in-depth information (*e.g.*, mental health services, developmental disabilities, special education, autism, and parent empowerment). Provider contact information organized by geography is available on the Children's Behavioral Health Services website. In addition, *Maine 211* also provides access to a comprehensive resource database. It would be useful to review this array of information and referral sources to make sure that visibility is adequate, that the assets of each are leveraged to their maximum advantage, and that information and referral is of consistent quality statewide.

- Linking with services

  Family organizations provide low barrier information about a range of supports and services. Also, for those that qualify for case management services, family driven planning provides a systematic process for linking people with a comprehensive array of needed services. However, for children who are not eligible for case management services, there is no systematic process across all entry points for linking people to a comprehensive array of services.

- Coordinated community and institutional eligibility determination

  There is no institutional level of care in Maine for children with mental disorders. For children with mental retardation, day habilitation services are available, as well as access to one ICF-MR. Children's Behavioral Health Services determines eligibility for habilitation services and the Division of Licensing and Regulatory Services determines eligibility for the ICF-MR facility, with judicial review in Probate Court.

- Coordinated clinical and financial eligibility

  The process of determining clinical eligibility for children's behavioral health services is not coordinated with the process of determining financial eligibility. Most people have already obtained their MaineCare eligibility by the time they are accessing children's behavioral health services.

  For people seeking MaineCare eligibility under the Katie Beckett eligibility category, a financial application and disability application are both submitted to a local DHHS office. An eligibility specialist determines financial eligibility and a medical review team determines whether or not the child satisfies SSI disability requirements. A nurse then contacts the family to set up a time to make the level of care determination.[112]

[112] Maine Department of Health and Human Services. January 2009. The Katie Beckett Benefit is a Way to Get MaineCare for Children with Serious Health Conditions (brochure).

- Family centered planning
  Children's Behavioral Health Services uses a wraparound planning model that is a family centered, highly individualized, strengths-based, planning process. Practice guidelines for case managers outline the elements of family centered planning and the role of the family in managing their life.[113]

  In recent years, OCFS has been working to enhance this planning model. OCFS has six providers implementing a "high fidelity wraparound" integrated planning approach at nine sites throughout the state. The Wraparound Maine Initiative serves children with serious emotional or behavioral disturbance who are involved with multiple state agencies (*e.g.*, children's behavioral health services, child welfare services, special education services or juvenile justice), and who are either in residential care or at high risk of placement in residential care. Each wraparound site is supported by a Community Collaborative Board and fidelity to wraparound principles is assessed.

- Tracking waiting lists
  Children's Behavioral Health Services monitors waiting times for certain children's services (case management, home and community based treatment services and children's habilitation services). The number of children waiting for an individual treatment plan in these services is also monitored.

Institutional Supply Controls

There is no institutional level of care in Maine for children with mental disorders. Residential treatment centers are the highest level of service available to children with serious emotional disturbances. These services are intended to be short term treatment, not a long term placement. Maine has one ICF-MR that serves children – the Elizabeth Levinson Center. The Levinson Center, which has 16 long term beds and 4 respite beds, was privatized as of March 1, 2009. Children may also access four ICF-MR beds in another private agency when needed.

- Privacy and autonomy considered
  The information in ADULTS WITH DEVELOPMENTAL DISABILITIES applies equally to ICF-MR services for children.

- Controls on supply
  The information in ADULTS WITH DEVELOPMENTAL DISABILITIES applies equally to ICF-MR services for children.

Transition from Institutions

- Identifying people for transitioning
  Discharge planning is inherent to the services delivered at the one ICF-MR serving children in Maine. In addition, by rule, a person 21 years old and older is not eligible for this facility.

- Funds transition planning
  A targeted case manager could be reimbursed for helping to arrange services in the community.

- Funding for one-time transition expenses
  Flex funds are available as resources allow and could be used for this purpose.

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[113] Maine Department of Health and Human Services, Children's Behavioral Health Services. 2005. Children's Targeted Case Management Practice Guidelines.

Continuum of Residential Options

- ◉ Privacy and autonomy considered
  Licensing rules for residential child care facilities include provisions that address privacy, communications, family involvement in planning, family communication, etc. These standards should be further evaluated to determine if they optimize privacy and autonomy as appropriate for the needs of the children served.

- ✕ Range of options.
  This element is not relevant for this population group – DHHS does not offer a range of residential services for children. They have redesigned their service system to provide intensive short term treatment. There are three different models of residential treatment facilities: family focused, staff intensive, and locked/secured.

- ✕ Up-to-date information about available options
  This element is not relevant for this population group – residential treatment is not promoted as a housing option. Access to residential treatment is carefully managed; people are referred to residential treatment only when their treatment needs meet the medical necessity criteria.

Long Term Services and Supports Infrastructure Development

- ● Case management
  CHBS offers case management services to this population group.

- ● Develops workforce to meet needs
  Workforce development is part of Children's Behavioral Health Services' quality program. Training focuses on keeping current with best practice and creating consistent statewide standards for credentialing unlicensed personnel. Children's Behavioral Health Services has developed an Other Qualified Mental Health Professional (OQMHP) certification that requires the staff person to meet competencies in specific areas. Competencies can be met through college courses, other certifications or specific trainings. For home and community based treatment services a defined curriculum and certification process has been developed for the Behavioral Health Professional (BHP). As of December 2008, there are 110 certified trainers and 555 certified BHPs and 112 provisionally certified BHPs.

- ◉ Support for informal caregivers
  Children's Behavioral Health Services provides respite and support groups for families. Respite is dependent on state general funds, which are usually not sufficient to meet demand.

- ● Uses evidence based practices
  Children's Behavioral Health Services has an Evidence-Based Practice Advisory Committee formed to research, evaluate and disseminate information regarding Evidence-Based Practices for behavioral health disorders of childhood. The committee is a sub-committee of the DHHS Evidence-Based Practice Coordinating Committee.[114]

- ● Stakeholders participate in planning for services
  Children's Behavioral Health Services involves families in planning and policymaking through a variety of mechanisms. For example, membership of the governing council for Wraparound Maine, the initiative to enhance wraparound planning, includes both family representatives and youth with current or previous

[114] Maine Department of Health and Human Services, Office of Child and Family Serivces. Children's Services Evidence-Based Practice Advisory Committee. http://www.maine.gov/dhhs/ocfs/cbhs/ebpac/index.shtml, accessed February 15, 2009.

involvement in Wraparound Maine. The governing council for Maine's trauma-informed system of care initiative, THRIVE, includes parent and youth membership. The Statewide Quality Improvement Council, funded by the Mental Health Federal Block Grant, has a children's subcommittee, which holds forums each year to elicit feedback on all aspects of the system of care. Stakeholders have helped to redesign in-home treatment services. DHHS has included families in Futures Search community meetings, in which participants were asked to help develop clear pathways for accessing services and supports. Children's Behavioral Health Services also supports five statewide and two county family organizations.

Evidence-Based and Best Practice for Children's Behavioral Health[115]

Evidence Based Practice	Implementation
Applied Behavior Analysis (ABA)	Providence's Merrymeeting Center for Child Development; Eastern Maine Counseling and Testing
Child Parent Psychotherapy (CPP)	Private practitioners only. List: http://thriveinitiative.org/ebp_cpp.php
Functional Family Therapy (FFT)	Spurwink Services; Catholic Charities, St. Michael's Center
Incredible Years (Parent groups only)	Northeast Occupational Exchange
Multidimensional Treatment Foster Care	Youth Alternatives/Ingraham
Multisystemic Therapy (MST)	Tri-County Mental Health Services; Kennebec Behavioral Health
Trauma-Focused Cognitive Behavioral Therapy	Youth Alternatives/Ingraham; Tri-County Mental Health Services; Support Solutions; Spurwink Services; Families United; Providence; St. Mary's Renaissance and Genesis Houses; Rumford Group Homes; Long Creek Youth Development Center
Best Practice	**Implementation**
Assertive Community Treatment Teams (ACT)	Maine Medical Center, The Anchor Program; Counseling Services, Inc (Springvale, Saco, Kittery, Westbrook); Community Health and Counseling Services, Inc (Bangor); Community Care (Bangor); Harbor Family Services (Rockland)
Dialectical Behavior Therapy (DBT)	Spurwink Services; Maine Medical Center/Spring Harbor Hospital; Harbor Family Services
Family Psychoeducation for Prodromal Schizophrenia	Maine Medical Center
High Fidelity Wraparound	Sweetser; Youth Alternatives; WINGS; Spurwink Services; Kennebec Behavioral Health; Catholic Charities
Modular Approach to Therapy with Children (MATCH)	Community Counseling Center; Counseling Services, Inc., Kennebec Behavioral Health
Portland Identification and Early Referral (PIER Program)	Maine Medical Center

[115] OCFS' contracted providers using evidence based practices researched on youth and "best practice," March 18, 2009.

Consumer Direction

○ Individualized budget

Each provider of children's day habilitation services has an agency rate; the intensity and frequency of service is dependent on the child's needs.

○ Option to hire own workers

Providers delivering in-home habilitation services consult with a family to find the right match; within the availability of the provider's staff parents may accept or reject a particular staff person. However, families do not have the option of hiring or firing their own direct support worker providing in-home services.

◉ Option to purchase goods and services

Under the Medicaid programs, families do not have the option to manage their service budget or purchase goods and services outside the standardized service package. Maine does have flex funds available; a family may apply to access those funds for a specific use. The average amount accessed is $300 annually.

Quality Management

◉ Quality management plan

Children's Behavioral Health Services' quality management plan includes conducting contract reviews, conducting program reviews, using family input collected by the QIC to improve services and continuing to participate in the Lean Management process. Children's Behavioral Health Services collaborates with the Division of Purchased Services to monitor provider contracts, including the requirement that providers develop and review an agency quality improvement plan. Most recently, the early intervention contracts were reviewed. Provider program reviews are conducted on site and through paper review as resources allow. OCFS has participated in several Lean Management processes that identify the current state, identify the gaps and develop a more efficient process to deliver services. Lean Management processes have been used to improve systems of care for children with PDD and for youth transitioning to adult services. The feedback obtained by the Statewide Quality Improvement Council on all aspects of the system of care also informs quality improvement.

◉ Quality measurements

OCFS has developed standards for residential services for children. Children's Behavioral Health Services has developed a statewide standardized process to improve delivery of day habilitation services, using a standardized comprehensive assessment and a standardized treatment form, and initiating a utilization review process. Children's day habilitation standards are near completion. Children's Behavioral Health Services works with the Office of Quality Improvement on targeted reviews. Past examples include an evaluation of case management services and behavioral health services, the results of which were used for a major redesign of the system.

◉ Consumer surveys

Children's services participate in DHHS Office of Quality Improvement annual consumer survey. In addition, a parent survey is being developed for day habilitation services.

System Components

See PROCESS AND APPROACH for an explanation of the criteria used to determine whether the key elements of the system components are present. Findings are summarized using the key to the right. This information is meant to provide a current, cross-population status report on where DHHS has already built its systems and where it is already addressing, has plans to address, or might consider addressing opportunities for improving these systems.

KEY	
●	All Key Elements in Place
◉	Some Key Elements in Place
○	Key Elements Not in Place
✕	Not Relevant to Population Group

The systems serving children with behavioral disabilities are distinct from those serving children with physical disabilities. The analysis of the system components is done separately for each.

Children with Physical Disabilities

Strategic Vision for Rebalancing

○ Vision statement
There is no program with overarching responsibility for serving children with physical disabilities.

◉ Monitors progress toward vision
There is no program with overarching responsibility for serving children with physical disabilities. As part of this profile, DHHS has developed definitions for three groups of children requiring long term supports and services including children with physical disabilities.

Consolidated State Agency

○ Shifting Resources
There is no program with overarching responsibility for serving children with physical disabilities.

◉ Coordinated policymaking
The Office of Elder Services and the Office of MaineCare Services coordinates planning, budgeting and policymaking for long term supports and services that serve children with physical disabilities. Although neither is charged with responsibility for addressing the needs of children, historically both have tried to do so.

◉ Uses data to plan for services
There is no program with overarching responsibility for planning for the long term supports and services for children with physical disabilities. To the degree that the Office of Elder Services and the Office of MaineCare Services use data to plan for in-home nursing and personal care services, kids would be included in the analysis.

Single Access Points

◉ Information and referral
211 Maine provides information and referral for a wide range of services, including home health services. It would be useful to review *211 Maine* to make sure that visibility is adequate and that information and referral is of consistent quality statewide.

○ Linking with services
There is no systematic process for reviewing options or linking this population group to a comprehensive array of services.

✕ Coordinated community and institutional eligibility determination
Home health agencies determine eligibility for children accessing home care services. Children are not admitted to nursing facility services.

◉ Coordinated clinical and financial eligibility
The process of determining clinical eligibility is not coordinated with the process of determining financial eligibility. For people seeking MaineCare eligibility under the Katie Beckett eligibility category, a financial application and disability application are both submitted to a local DHHS office. An eligibility specialist determines financial eligibility and a medical review team determines whether or not the child satisfies SSI disability requirements. A nurse then contacts the family to set up a time to make the level of care determination.[116]

◉ Family centered planning
Providers can and do work with a family to help them identify goals and build an array of formal and informal supports to achieve those goals. However, doing so is a matter of individual practice, not a programmatic requirement.

○ Tracking waiting lists
There is no program responsible for tracking waiting list for home health services for this population group.

Institutional Supply Controls

✕ Privacy and autonomy considered
Children with physical disabilities are not served in nursing facilities.

✕ Controls on supply
Children with physical disabilities are not served in nursing facilities.

Transition from Institutions

✕ Identifying people for transitioning
Children with physical disabilities are not served in nursing facilities.

✕ Funds transition planning
Children with physical disabilities are not served in nursing facilities.

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[116] Maine Department of Health and Human Services. January 2009. The Katie Beckett Benefit is a Way to Get MaineCare for Children with Serious Health Conditions (brochure).

✖ Funding for one-time transition expenses
Children with physical disabilities are not served in nursing facilities.

Continuum of Residential Options

✖ Privacy and autonomy considered
Children with physical disabilities are not served in residential facilities.

✖ Range of options
Children with physical disabilities are not served in residential facilities.

✖ Up-to-date information about available options
Children with physical disabilities are not served in residential facilities.

Long Term Services and Supports Infrastructure Development

◉ Case management
Unless eligible through another program, children with physical disabilities do not have access to MaineCare funded case management services. Care management may be available if the child meets the eligibility criteria. The CSHCN program provides care coordination for medical and other services to children having one of the specific conditions covered under that program.

◉ Develops workforce to meet needs
This population group benefits from workforce initiatives under programs serving other groups. For example, children would benefit from many of the workforce development initiatives improving the quality and supply of in-home direct support workers. These initiatives are described under OLDER ADULTS AND ADULTS WITH DISABILITIES.

○ Support for informal caregivers
No supports for caregivers are available unless the child is eligible under another program.

○ Uses evidence based practices
This population group may benefit from evidence-based practices introduced by other programs. However, no evidence-based practices targeting home health services for this group were identified.

○ Stakeholders participate in planning for services
There is no program responsible for soliciting stakeholder input on policymaking or other aspects of services for this group.

Consumer Direction

● Individualized budget
Services are portable among providers; DHHS uses standardized rates for home health services.

◉ Option to select own workers
Families may access the Family Provider Service Option (FPSO) described under OLDER ADULTS AND ADULTS WITH DISABILITIES.

○ Option to purchase goods and services

The option to manage a service budget or purchase goods and services outside the standard service package is not available for this population group.

Quality Management

- ◉ Quality management plan
  Children with physical disabilities are included in the group of services monitored by the Office of Elder Services. However, OES' quality management plan does not focus specifically on kids.

- ◉ Quality measurements
  Children with physical disabilities are included in the group of services monitored by the Office of Elder Services. However, OES' quality management plan does not focus specifically on kids.

- ○ Consumer surveys
  It is not clear that consumer surveys are administered.

Other Services

Other Services

Department of Education

The Department of Education is the State Educational Agency responsible for carrying out Maine's responsibilities under the Individuals with Disabilities Education Act (IDEA). IDEA governs ChildFind, the process of identifying children with disabilities; early intervention services; and special education.

Child Development Services

DOE contracts with 16 regional sites to form the Child Development Services (CDS). The CDS system provides early intervention for ages birth to two and Free Appropriate Public Education (FAPE) for ages three - five years. Each CDS provides case management and direct instruction for children birth through age five and their families. They also conduct ChildFind through screenings and evaluations for children birth through age five. CDS provides early intervention and special education programming in the following areas:

- Physical gross and fine motor skills
- Cognitive
- Communication (speech and language)
- Social and emotional
- Adaptive

Special Education

DOE promulgates regulations governing special education services and gathers data on the services received. In 2007, special education services comprised 15% of all educational enrollments in Maine.[117]

Total Number of Students Age 3-21 Receiving Special Education by Disability and Percent[118]

Disability	Count	% of Total
Mental Retardation	846	2.38
Hearing Impairment	215	.6
Deafness	60	.17
Speech and Language Impairment	9,118	25.64
Visual Impairment including Blindness	92	.26
Emotional Disability	3,118	8.77
Orthopedic Impairment	68	.19
Other Health Impairment	5,325	14.97
Specific Learning Disability	10,648	29.94
Deaf-Blindness	10	.03
Multiple Disabilities	3,152	8.86
Developmentally Delayed	1,069	3.01
Autism	1,760	4.95
Traumatic Brain Injury	83	.23
Totals	35,564	100%

[117] Maine Department of Education, Special Services Information. Students with Disabilities: Maine Child Count Data Ages 3-21, 1986-2007. Accessed from http://www.maine.gov/education/speceddata/14yeardata.htm on March 28, 2009.
[118] Maine Department of Education, Special Services Information. December 1 Child Count/Percent to Total by Disability. Accessed from http://www.maine.gov/education/speceddata/percentchart.htm on March 28, 2009.

Special education services include case management, transportation, technological aids, communication services, mental health services, physical restoration services, family services, independent living services, residential living services, vocational training, etc.

Department of Labor

The Bureau of Rehabilitation Services administers several programs serving people with disabilities.[119] Of the people served, the major categories of disabilities were:

Mental illness	35%
Cognitive disability	28%
Physical disability	23%
Blind or visually impaired	8%
Deaf/hard of hearing	5%

Services provided are described below.

Vocational Rehabilitation Services

Division of Vocational Rehabilitation Services (DVR). DVR provides individual counseling and guidance, vocational assessment, independent living, supported employment, etc. DVR placed 730 people in employment in 2008. Supported employment funded under this program ends after two years. DHHS offers supported employment to adults with severe and persistent mental illness and adults with mental retardation or autism. Persons with brain injury do not have access to supported employment after the two years are over.

Division for the Blind and Visually Impaired (DBVI). DBVI provides vocational rehabilitation services for working aged adults who are blind or visually impaired. Services include individual vocational counseling and guidance, vocational assessment, orientation and mobility instruction, low vision services, etc. DBVI served 713 people in 2008.

Independent Living Services

Independent Living Services Independent living services include information and referral, individual independent living skills training, peer counseling, and individual and systems advocacy. In addition, the program can purchase products and services, including home modifications, hand controls and lifts for vehicles, augmentative communication devices, telecommunication devices for the deaf (TTYs), counseling services, and mobility training. Purchases are capped by a maximum lifetime expenditure of $5,000 for each eligible individual.

Division for the Blind and Visually Impaired. DBVI provides individual counseling, guidance related to adjusting to blindness, use of adaptive technology, adaptive skill training, orientation and mobility instruction, etc. The DBVI Independent Living program provided independent living services to more than 400 individuals in 2008. DBVI also served 280 children, providing specialized educational services, use of adaptive technology, adaptive skill training in communication, orientation and mobility, etc.

Deaf Services

Division on Deafness. The Division of Deafness administers the Telecommunications Equipment Program, which provides telecommunication equipment to all people with disabilities enabling access to telephone services. The Division also provides information and referral and advocacy services. This past year 342 people received direct services.

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[119] Information about Department of Labor services were obtained from Maine Department of Labor, Bureau of Rehabilitation Services. 2007-2008 Highlights.

Maine State Housing Authority

Maine State Housing Authority finances subsidized housing, including subsidized housing for the elderly and persons with disabilities. More than half of its subsidized housing units serve the elderly – as of 2007, subsidized housing units were categorized as follows:

Family Units	13,217
Elderly Units	15,477
Disabled Units	466
Special Needs Units	1,849
TOTAL	30, 979

In addition to financing the construction of subsidized housing, MSHA and local housing authorities administer the Section 8 rental assistance voucher programs.

MSHA also finances homeless shelters and plays a leading role in addressing homelessness, partnering with DHHS to address mental health, substance abuse, and other service needs of persons who are homeless. Maine's most recent Annual Point in Time Survey documented the number of people who were homeless on the night of January 28, 2009. Of 765 respondents, 32% reported that they had a chronic disability, 16% reported severe and persistent mental illness, and 16% reported chronic substance abuse.[120]

[120] Maine State Housing Authority. 2009. 871 People Homeless in Maine on January 28, 2009: Annual Point in Time Survey.

Appendix A

Draft Settings Characteristics Assessment Tool

Draft Settings Characteristics Assessment Tool

On the following pages is a draft assessment tool developed collaboratively with the Project Team, with review and input provided by the Stakeholder Advisory Group. This tool includes some preliminary thoughts on how one would begin to assess a setting for the characteristics that are important to deciding whether it's an institution in the "restrictive" sense of the word rather than an institution by virtue of the level of care it provides. The tool below would be used to evaluate settings (other than settings where the individual is responsible for housing costs, *i.e.*, a person's own home or apartment).

In the next phase of this project, the Project Team will explore ways to use these (or a modified version of these) characteristics in assessing existing institutional and residential settings or shaping DHHS' standards for institutional and residential services in the future. Some questions under discussion:

- Are these the right characteristics? Is this a workable tool?
- Can these characteristics be used to evaluate existing residential settings so that DHHS can assess the nature of their institutional and residential services and whether or not their resources are distributed according to their programmatic goals?
- Or should it be a tool used by consumers to evaluate institutional or residential settings?
- Can these characteristics be used to develop a rating system that identifies where the setting falls along a continuum of least to most restrictive?
- Can these characteristics be used to shape DHHS' licensing and purchasing policy across settings?

Although still a work in progress, the tool is included in this document to raise its visibility and invite input and discussion.

Draft of Tool for Evaluating Restrictiveness of Settings

Type of Facility or Residence[121]		
The residence consists primarily of:		
☐ Apartments	☐ Yes	☐ No
☐ Private rooms with private bath	☐ Yes	☐ No
☐ Private rooms with shared bath	☐ Yes	☐ No
☐ Semi-private rooms with shared bath	☐ Yes	☐ No
Privacy: Control Over Space		
☐ Control over entry to personal space (room or apartment)	☐ Yes	☐ No
☐ Able to enter or exit certain areas/units without restriction	☐ Yes	☐ No
☐ If no, is this due to safety concerns (*e.g.* people with dementia)	☐ Yes	☐ No
☐ Able to enter & exit building anytime (not locked or monitored)	☐ Yes	☐ No
☐ If no, is this due to safety concerns (*e.g.* people with dementia)	☐ Yes	☐ No
Privacy: Private Communications		
☐ Private space for communications	☐ Yes	☐ No
Autonomy: Personal Space		
☐ Able to bring and arrange furniture	☐ Yes	☐ No
☐ Able to store food	☐ Yes	☐ No
☐ Able to prepare individual snacks or meals	☐ Yes	☐ No
☐ Able to control individual unit temperature	☐ Yes	☐ No

[121] May need to add information on number of units/rooms that are apartments, private or semi-private.

Autonomy: Communications		
☐ Able to access to phone, mail, other communications at anytime (no restrictions)	☐ Yes	☐ No
Autonomy: Visitors		
☐ Visitors welcome at all times (no restrictions)	☐ Yes	☐ No
Autonomy: Other Public Space		
☐ Indoor public space available for entertainment, activities, TV	☐ Yes	☐ No
☐ Outdoor space available	☐ Yes	☐ No
Autonomy: Access to Community		
☐ Able to access community space and events (*e.g.* able to walk or arrange transportation to stores, events, church, etc).	☐ Yes	☐ No
Autonomy: Kitchen		
☐ Access to private kitchen	☐ Yes	☐ No
☐ Access to communal kitchen	☐ Yes	☐ No
Autonomy: Dining Space		
☐ Private dining area (able to eat in own room/apartment some or all of the time)	☐ Yes	☐ No
☐ Communal dining area with choice of seating	☐ Yes	☐ No
☐ Communal dining area with no choice of seating	☐ Yes	☐ No
Autonomy: Meal Schedule		
☐ Meal times ☐ Flexible ☐ Scheduled		
☐ Residence provides:		
☐ 0 meals a day		

☐ 1 meal a day		
☐ 2 meals a day		
☐ 3 meals a day		
Autonomy: Housekeeping		
☐ Individual arranges or does own housekeeping	☐ Yes	☐ No
☐ Individual arranges or does own laundry	☐ Yes	☐ No
Autonomy: Activities		
☐ Individual controls and arranges own activities	☐ Yes	☐ No
☐ Individual expresses preferences for activities – Provider arranges activities	☐ Yes	☐ No
☐ Provider plans, conducts and/or arranges group activities	☐ Yes	☐ No
Environment: Staff Philosophy		
☐ Staff trained to provide person centered care/services	☐ Yes	☐ No
☐ Person able to choose direct-care staff	☐ Yes	☐ No
Environment: Size of Setting		
☐ Over 16 unrelated persons sharing unit *OR*	☐ Yes	☐ No
☐ 11-16 unrelated persons sharing unit *OR*	☐ Yes	☐ No
☐ 5-10 unrelated persons sharing unit *OR*	☐ Yes	☐ No
☐ 1-4 unrelated persons sharing unit *OR*	☐ Yes	☐ No

Nature of Services and Populations Served

The following information could be collected on the types of needs people have in the setting, as well as the types of services provided by a Provider/setting. This information would help in the analysis of the data and would allow for comparisons of types of settings by the types of services provided and/or the types of people served.

People are admitted or served who…		
☐ Have dementia	☐ Yes	☐ No
☐ Have behavior symptoms	☐ Yes	☐ No
☐ Have urinary incontinence	☐ Yes	☐ No
☐ Need help with activities of daily living	☐ Yes	☐ No
☐ Have brain injury	☐ Yes	☐ No
☐ Have intellectual disabilities	☐ Yes	☐ No
☐ Other: _____	☐ Yes	☐ No
Services arranged or provided by Provider include:		
☐ 24 hour staff supervision	☐ Yes	☐ No
☐ Medication administration/assistance	☐ Yes	☐ No
☐ Any personal care	☐ Yes	☐ No
☐ Any nursing care	☐ Yes	☐ No
☐ Other:_____	☐ Yes	☐ No

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Appendix B

System Components Key Elements – Rationale

System Components Key Elements – Rationale

The State Profile Tool Technical Assistance Guide identifies several system components associated with a balanced long term supports and service system. The key elements for these system components were identified with the guidance and input of the Project Team and Stakeholder Group. The rationale for selecting these elements is provided below.

Strategic Vision for a Balanced System

Vision Statement. A strategic vision provides a common reference point for decision making at all levels of an organization, facilitating the alignment of policy and practice around a common goal. To be effective, an organization's vision needs to be communicated and reinforced by leadership. In this context, the question is whether Maine has a vision for a balanced long term support system – does Maine articulate a vision for a long term support system that incorporates a comprehensive community service system? A vision for a long term support system may be embodied in statute, a consent decree, or other governing documents. Or a vision could be specifically articulated as a DHHS vision for services.

> *Key Elements:* DHHS has a vision statement for a person centered system of long term services and supports. The vision statement:
> - Defines DHHS' commitment to a comprehensive community service system, consumer choice and self-direction, and providing services in the most integrated setting appropriate to needs and preferences.
> - Is communicated to internal and external audiences.
> - Is used to guide policy and budgeting decisions.

Monitors Progress Toward a Vision. A meaningful commitment to a vision is backed up with a systematic approach to measuring progress toward this vision: Has DHHS defined measures for achieving its vision? Does it monitor progress for achieving that vision? Defining the population groups that receive long term services and supports is an important element of defining a vision. For example, not everyone receiving mental health services needs or receives long term services and supports. Similarly, many people with brain injury may need intensive services and supports for a short period of time but recover to the point where services and supports are not needed over the long term. Having consensus on who falls into the long term services and supports population groups will foster more consistent decision making on the best way to serve these groups. As part of this project, DHHS has largely completed this step for all of its primary population groups receiving long term services and supports.

> *Key Elements:* DHHS measures and monitors its progress toward achieving its vision:
> - DHHS has an agreed upon definition for population groups, services and units of service for reporting and planning of long term services and supports.
> - DHHS has defined measures for monitoring progress.
> - DHHS monitors progress against its measures.

Consolidated State Agency

Shifting Resources. A study of the organizational structures of several states found that successfully balancing resources across settings is tied to whether one entity has the ability to move money between institutional budgets and home and community based budgets, across programs and across population groups.[122]

[122] Kane, Rosalie and Robert Kane, Martin Kitchener, Reinhard Priester and Charlene Harrington. 2006. State Long Term Care Systems: Organizing for Rebalancing State Long-Term Care Systems, Topic Paper No. 2.

Key Element: DHHS has a unified budget for long term services and supports that can be transferred across institutional, residential and home and community based services within a budget cycle.

Coordinated Policymaking. That same study found support for merging management of institutional and community based care into one agency. Common management enabled greater focus on rebalancing, better accountability for outcomes and more flexible management of budget allocations and reallocations. [123] Some of the management functions that benefit from integration include planning and policymaking, *e.g.*, planning for growth, setting goals and targets.

Key Element: Programmatic, budgetary, and oversight responsibility for institutional and home and community based services is consolidated with a single point of accountability; or highly coordinated across multiple points of accountability.

Uses Data to Plan for Services. We want to know whether DHHS uses data to anticipate demand for the supply of institutional, residential and home and community-based services, given anticipated changes in demographics or policy.

Key Element: DHHS uses data on supply and the demand for long term services and supports to plan for the future; to anticipate and plan for the availability of a qualified workforce.

Single Access Points

Information and Referral. Sorting among a range of community options can be complicated and confusing, while institutional options can be highly visible. To balance out this bias toward the institutional option, it's important that people have streamlined access to information about community services. To be effective, information and referral needs to be visible, offer access to a comprehensive resource database, and provide consistent information.[124]

Key Elements: Identifiable organizations provide information and referral on the range of available community and institutional options:

- The organization is a visible & trusted place for people to obtain information regarding the full range of long term services and supports.
- The organization accesses a comprehensive and up-to-date resource database for options in service area.
- Staff provides consistent & uniform information.
- Providers of general and specialized information and referral play coordinated and complementary roles to access to information and referral is of consistent quality statewide.

Linking with Services. For many people, access to information and referral services is enough. They already know enough about their options and they just need discrete information. Other people, however, may require a higher level of services. They might need help sorting out what their questions are, what their options are, and how to translate this information into a plan. Having this level of service available – something short of case management and before one applies for public services – offers people an opportunity to consider the pros and cons of a full range of choices, including private pay options and informal and community services and supports. This level of service is consistent with the "assistance" provided by an Aging and Disability Resource Center.[125]

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[123] Ibid.

[124] Aging and Disability Resource Center Technical Assistance Exchange. 2007. Fully Functioning Criteria for Single Entry Point System – ADRC.

[125] For more information about Aging and Disability Resource Centers, see http://www.adrc-tae.org/.

Key Elements: DHHS uses systematic processes to make sure people understand the full array of services that might be available to them, including housing and residential services, income supports, caregiver supports, etc.

- DHHS has a process in place to educate staff, consumers and providers about long term services and supports.
- Consumers are assisted in identifying appropriate options in the context of their individual needs, preferences, values and circumstances.[126] Access to this assistance is "low barrier," *i.e.*, a person does not have to access case management services in order to find out what service options are available to him or her.

Coordinated Community and Institutional Eligibility Determination. Once a person enters an institution it can be difficult to move back into the community; people are more likely to live successfully in the community if they can avoid ever transitioning into a nursing facility in the first place.[127] People are better able to understand their full range of choices available to them when the process for determining eligibility for institutional care is coordinated with the process for determining eligibility for home and community based services. This is especially important when people have preconceived ideas that institutional care is their only viable option.

Key Elements: Before a consumer with long term support needs is admitted to an institution, DHHS ensures that the consumer has an opportunity to choose among the full range of options available to that individual.

Coordinated Clinical and Financial Eligibility. Coordination between the clinical and financial eligibility process can play a role in determining the setting in which an individual is served. The process of determining clinical or functional eligibility for services is usually faster than the process of determining financial eligibility. For example, there is some evidence that nursing facilities more readily admit people while Medicaid eligibility is pending because nursing facilities have better capacity to assess the likelihood that a person will be determined eligible.[128] Smaller community providers are faced with greater uncertainty about whether a person will be able to pay for their services and are more likely to deny. As a result, the path of least resistance for a person being discharged from a hospital might lead to a nursing facility.

Other states have used different strategies to better align these two eligibility processes. These include: assisting consumers as they prepare their applications; making applications available electronically, including electronic submission of applications; and co-locating the specialized eligibility staff for these two processes so that they can coordinate the application processes more easily.[129] Where a determination of disability is a required step in determining financial eligibility (*e.g.*, under SSI or SSI-related), the process can also be delayed. Preparing the application and accessing the medical records needed to support the application can be a barrier to access for some people.[130]

Key Elements:

- DHHS facilitates the process of determining financial eligibility by providing information and support for completing the MaineCare application for long term care or based on disability.
- DHHS coordinates the process for determining financial eligibility for long term services and supports with the process of determining clinical eligibility for long term services and supports.

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[126] National Association of State Units on Aging. 2007. Long-Term Support Options Counseling: Decision Support in Aging and Disability Resource Centers.
[127] Alecxih, Lisa. 2005. ADRC Roles in Rebalancing Long Term Care Systems: Diversion Initiatives.
[128] Mollica, Robert. 2004. Expediting Medicaid Financial Eligibility. Community Living Exchange Collaborative.
[129] Ibid. Some states were able to dramatically decrease the average time to make an eligibility determination when applications were completed with the help of case manager or eligibility specialist during a home visit.
[130] Stakeholder Meetings. May 19, 2008. Mapping Access to Mental Health Services for Maine's Systems Transformation Grant; and November 5, 2008. Mapping Access to Brain Injury Services for Maine's Systems Transformation Grant.

Person or Family Centered Planning. Person and family centered planning represents a philosophical shift in the way public services are offered to an individual. Person or family centered planning focuses on the goals of the individual or family and building on existing strengths and assets. It is a mechanism for helping to ensure that people have what they need, through both formal and informal supports, to achieve their goals. Because it is more comprehensive in scope than the services provided under a particular program, person or family centered planning can help to address barriers to successfully implementing a service plan.

Key Elements: There is a structured process for person or family centered planning:

- The person or family is involved in the planning process.
- Planning builds on a person's or family's goals, strengths and interests.
- Planning builds on personal relationships with friends, family and neighbors, as well as paid professionals.
- DHHS has a process for monitoring progress toward plan goals and updating the plan on a regular basis.
- Agencies and workers are trained on principles of person centered planning.

Tracking Waiting Lists

Access to services is also a function of their availability. Managing waiting lists is important for knowing whether services are adequate to meet the demand as well as making sure that people are able to access needed services in as orderly a way as possible.

Key Element: DHHS has a system for gathering and monitoring waiting list information on key services. DHHS has standards for managing waiting lists, *e.g.,* standards for frequency for updating waiting list information or standards for accepting names on a waiting list.

Institutional Supply

Privacy and Autonomy Considered. As part of this project, key characteristics were identified distinguishing most restrictive settings from least restrictive settings. It was agreed that these characteristics could be factored into DHHS policy governing institutional provider characteristics (*e.g.*, purchasing or licensing standards). In addition, ideally, DHHS would have information on these characteristics for each of the institutional settings that it funds. This information could be used to assess how well institutional service settings align with DHHS programmatic goals for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served.

Key Elements:

- Licensing or purchasing standards define requirements for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served.
- DHHS uses data on the characteristics of its residential options (*e.g.*, information on the types and characteristics of the settings, including level of privacy, level of personal control, and size) to make policy decisions about whether its institutional options meet programmatic goals for most integrated setting.

Controls on Expanding Supply. The supply of institutional services can often influence demand – because there are fixed costs associated with an institutional setting, the cost of providing services might not go down very much when the number of residents (and associated revenue) is reduced. As a result, when there are empty beds in an institution or another setting, there may well be pressure on the system to fill those beds so that an institution has needed revenue to provide services.

Key Elements: DHHS has specified criteria that must be met and an approval process for expanding supply of institutional beds (*e.g.*, CON process). DHHS has created incentives for reducing the supply of institutional beds.

Transition from Institutions

Identifying People Interested in Transition. The template asks whether there is a process for identifying people who are interested in transition. This process would be distinguished from a periodic reassessment conducted to determine whether or not a person is still eligible for institutional services. Instead, the process would focus on people who might still be eligible for institutional services but would prefer residing in a home or community-based setting. The *Money Follows the Person Toolbox* identifies some strategies for identifying people interested in transitioning, including: contacting each person in a nursing facility that responds positively to a standardized question about wishing to relocate; or analyzing data on health conditions and functional capacity to identify people who could access available community options.[131]

Key Element: DHHS has a process for identifying people interested in transitioning from an institution.

Funding for Transition Planning. The longer a person stays in an institutional setting, the harder it is to move out. The longer a person is in an institutional setting, the more likely he or she is to lose a house or apartment, along with the furnishings and personal belongings that make a home. Finding a place to live and setting up a new home can be a major barrier to moving out of an institution. Transition planning would include more than what is typically provided as part of discharge planning. Transition planning would include assistance with finding housing, establishing financial and clinical eligibility for services; coordinating the array of services and providers that will be needed on or shortly after the move; and arranging for transition services that are needed in order to move (*e.g.*, arranging utility hook-up; arranging for home modifications; etc.).[132]

Key Elements: DHHS funds transition planning from institution to home. Assistance includes:

- Assistance with establishing financial and clinical eligibility for services for home and community based services.
- Coordinating the array of services and providers that will be needed on or shortly after the move.
- Arranging for transition services that are needed in order to move (*e.g.*, arranging utility hook-up. arranging for home modifications; etc.).

Funding for One-Time Transition Costs. Funding for one-time transition costs facilitates transitions including potentially security deposits, essential furnishings, set-up fees and deposits for utilities, etc.[133]

Key Elements: DHHS provides funding for one-time transition expenses (*e.g.*, security deposits, essential furnishings, set-up fees and deposits for utilities, etc.).

Continuum of Residential Options

Privacy and Autonomy Considered. As part of this project, key characteristics were identified distinguishing most restrictive settings from least restrictive settings. It was agreed that these characteristics could be factored into DHHS policy governing residential provider characteristics (*e.g.*, purchasing or licensing standards). In addition, ideally, DHHS would have information on these characteristics for each of the residential settings that it funds. This information could be used to assess how well residential service settings align with DHHS programmatic

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[131] Mollica, Robert and Susan Reinhard, Jennifer Farnham, and Michael Morris. 2006. Money Follows the Person Toolbox. Community Living Exchange, Rutgers Center for State Health Policy and the National Academy for State Health Policy.
[132] Ibid.
[133] Ibid.

goals for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served.

Key Elements:

- Licensing or purchasing standards define requirements for optimizing individual privacy and control over environment and personal space, as appropriate for the needs of the individual served.
- DHHS uses data on the characteristics of its residential options (*e.g.*, information on the types and characteristics of the settings, including level of privacy, level of personal control, and size) to make policy decisions about whether its residential options meet programmatic goals for most integrated setting.

Range of Options. Long term services and supports can be provided in an individual's own home or apartment; in a subsidized apartment with assisted living or supportive services; a family or shared living arrangement in which the consumer shares a residence with a family or individual who is paid to provide support services; or residential services provided in a group setting.

Key Element: DHHS provides a range of residential options that includes supported services in an individual's own home; supportive housing, and a range of residential services.

Information about Housing. The State Profile Tool Technical Assistance Guide asks whether "information on affordable, accessible housing is readily available." We referenced *A Comparison of State Housing Locator Web Sites*[134] to identify the type of information that should be readily available.

Key Element: Consumers can access a database with accurate and up-to-date information about affordable and accessible housing and residential options that includes search fields for: target population; current vacancies; unit cost or rents; acceptance of rental assistance; geographic location; physical accessibility.

Long Term Services and Supports Infrastructure Development

Case Management. For people who are eligible, a case manager can play a major role in facilitating access to services. The scope of case management services can vary widely. However, the essential elements include assessing an individual's need for services, developing a service plan, and facilitating and monitoring implementation of the service plan. Case management is especially important for people with complex needs or people with cognitive disabilities that limit their ability to manage their own care.

Key Element: Case management services are available to facilitate access to community-based long term services and supports.

Develops Workforce. Direct support workers provide the majority of long term services and supports. Depending on the needs of the person they serve, they can provide a range of services from "hands-on" physical assistance, to skill development, to assistance with managing safe and responsible behavior. Because of its important role in a long term support system, the supply and quality of the direct care workforce is a critical part of home and community based infrastructure developments. Factors affecting the recruitment and retention of workers include: low wages, limited or no benefits, high workloads, unsafe working conditions, inadequate training, lack of respect from supervisors, few opportunities for advancement and lack of control over their jobs.[135]

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[134] Ray, Anne L. and Virginia Battista. 2004. A Comparison of State Housing Locator Web Sites Shimburg Center for Affordable Housing. College of Design Construction and Planning, University of Florida.

[135] Wright, Bernadette. 2005. Direct Care Workers in Long-Term Care: A Research Report. AARP Public Policy Institute. Accessed from http://www.aarp.org/research/longtermcare/nursinghomes/dd117_workers.html on March 21, 2009.

Key Elements: DHHS evaluates and addresses the quality and supply of the direct care workforce.

- DHHS sets standards for and supports training for the direct care workforce to meet needs of population group.
- DHHS monitors the adequacy of the workforce supply and takes steps to improve recruitment and retention.

Support for Informal Caregivers. Informal caregivers, including family, friends and neighbors, can play an important role in helping someone live at home or in the community. The majority of older adults living in the community depend on informal supports. Taking care of or coordinating care for children can exceed the usual role of a parent when a child has a serious medical or disabling condition. And many older adults continue to play this role for their adult children with a disability. For caregivers who play a major role in providing services, there can be health and economic consequences; providing supports can help to sustain the benefits and rewards of their role. Caregiver supports can include respite care, information and referral, care management, education and training, cash grants, and an array of other services.[136]

Key Element: DHHS has policies and programs that support informal caregivers, including respite, information and referral, support groups, or education and training.

Uses Evidence-Based Practice. Services that are supported by research are most likely to yield positive results. For many services, there is a growing body of "evidence based practices" that have been shown to improve outcomes, as well as promising and emerging practices. Part of building and maintaining a quality service system includes making sure that these model practices become standard practice.

Key Element: DHHS selects and implements evidence-based practices to enhance the quality of services.

Stakeholders Participate in Planning for Services. Consumers are the experts on their needs and preferences. They can provide important insights to inform the design of services and delivery models, helping to identify barriers to effective implementation.

Key Element: DHHS involves stakeholders in designing services and delivery models, and informing policy decisions.

Consumer Direction

Individualized and Portable Budgets. When an individual budget is based on provider-negotiated cost reimbursement, the budget is calculated by asking "What does the provider need to support this individual?" rather than "What supports does this individual need?" While a person might have an "individual" budget under this process, it is not truly a consumer-centered budget. Without a standardized approach toward calculating the budget, the results are not necessarily consistent or fair, depending to some degree on the negotiating skill of the provider. In addition, while theoretically portable, an individual budget based on one provider's negotiated costs may or may not be sufficient to cover those of another. As a result, individuals lack control over choice of provider or how money is spent.

Key Elements: DHHS has the building blocks for consumer directed services: DHHS can build a portable individual budget for services using a standardized method for allocating resources based on individual need for services.

Options to Hire Own Workers. Consumer directed programs serve multiple ends – they give consumers greater control over the decision of who will provide their services. They also expand the available labor supply when a

[136] Family Caregiver Alliance. 2004. The State of the States in Family Caregiver Support: A 50-State Study.

consumer can hire family and friends. Consumers have found their directly hired workers to be more reliable and sensitive to their specific needs.[137]

> *Key Element:* The consumer has an option to hire their own direct care workers.

Option to Purchase Goods and Services. Consumers given cash allowances for the purchase of goods and services (*e.g.*, laundry services, specialized medical equipment, or a microwave) value the flexibility to better meet their individualized needs and maximize the value of the public dollars being spent.[138]

> *Key Element:* The consumer has the option to manage his or her own budget and purchase goods and services outside the standard service package.

Quality Management

Quality Management Plan. CMS has recognized the key components of quality management in its HCBS waiver application.[139] These components include the development of a quality management strategy that outlines who is responsible for oversight and monitoring, the methods for data collection, and the process for using and updating the plan periodically, and the process for identifying areas for quality improvement. While developed for use in HCBS waivers, these principles are applicable to the broader set of services provided to these population groups.

> *Key Elements:* DHHS develops and uses a quality management plan for each population:
> - The roles and responsibilities for overseeing quality are clearly defined.
> - The quality management plan is updated periodically.

Quality Measurement. Quality measures are widely recognized as necessary components of any quality management system. This generally requires the identification of quality indicators that can be used to monitor performance and remediate problems. Quality measures that include benchmarks or trends over time provide a way to evaluate program performance and assess system improvement.[140]

> *Key Elements:* DHHS uses quality measurement information to inform program performance and system improvements:
> - Quality indicators have been identified.
> - Quality measures are reviewed on an ongoing basis.

Consumer Surveys. The voice of consumer participants is a crucial component in understanding the experience of people receiving services. Consumer surveys provide a way to obtain participant perspectives on the effectiveness, efficiency and adequacy of services.

> *Key Element:* DHHS routinely asks participants about their satisfaction with services and supports (*e.g.,* consumer surveys are conducted).

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[137] Simon-Rusinowitz, Lori, Dawn Loughlin and Keven Mahoney. 2006. Do Consumers get Good Quality Care in Consumer-Directed Program? Experience from a Cash and Counseling Evaluation.
[138] Ibid.
[139] HCBS Waiver Application Version 3.5
[140] Booth, M., Fralich, J.. April 2006. Performance Measurement: Managing and Using Home and Community-Based Services Data for Quality Improvement. The Community Living Exchange Collaborative at Rutgers Center for State Health Policy and the National Academy for State Health Policy.