

What We Have Now

a reference tool developed for Maine's Work Group for Community-Based Living

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Introduction

This section describes most of the public programs administered by the Maine state government that support people with disabilities. Although not created as one comprehensive plan for serving people with disabilities, these multiple programs are compiled here into one document. Looking across departments, this section describes the state agencies that play a role in providing services for people with disabilities and the collage of programs that support home and community living for both children and adults. Described are:

- health and mental health services;
- supportive services;
- educational services;
- housing;
- transportation; and
- employment.

We have written this document to serve as a foundation for ongoing efforts to improve services, so have made some effort to write this section as a reference tool as well.

The People Served

Usually the people served by the State have needs that can only be met by accessing services across more than one state agency. The table below illustrates the different state and public agencies that might provide services to a child or an adult. Depending on program eligibility criteria, a child or adult will not necessarily be served by all of the child- or adult-serving programs.

Table 1. State and Public Agencies that Provides Services to Children and/or Adults

| Department or Agency | Children | Adults |
|--|----------|----------------|
| Department of Behavioral and Developmental Services (BDS) | | |
| Adult Mental Health Services | | ✓ |
| Adult Mental Retardation Services | | ✓ |
| Children's Services | ✓ | |
| Substance Abuse Services | ✓ | ✓ |
| Department of Corrections (DOC) | | |
| Probation | ✓ | ✓ |
| Correctional facilities | ✓ | ✓ |
| Department of Education (DOE) | | |
| Special Services Team | ✓ | ✓ ¹ |
| Adult Education Team | ✓ | ✓ |
| Department of Human Services (DHS) | | |
| Bureau of Child and Family Services (BCFS) | ✓ | |
| Bureau of Elder and Adult Services (BEAS) | | ✓ |
| Bureau of Family Independence (BFI) | ✓ | ✓ |
| Bureau of Health (BOH) | ✓ | |
| Bureau of Medical Services (BMS) | ✓ | ✓ |
| Department of Labor (DOL) | | |
| Bureau of Rehabilitation Services | ✓ | ✓ |
| Department of Transportation (DOT) | ✓ | ✓ |
| Maine State Housing Authority or Public Housing Authority | ✓ | ✓ |

¹ A person who has not received a regular high school diploma and is 20 years old at the beginning of the school year could be receiving special education services.

The Role of State Government

The state government plays multiple roles in providing and influencing the services provided to people with disabilities. In some cases, the state government is the vehicle for implementing programs governed by federal law. In other cases, the state government creates its own programs (which are also subject to federal laws, such as the Americans with Disabilities Act). Funding may come from federal funds, from state funds with a federal match, or from state funds only.

Tools for Shaping the Services Delivered

Working within the statutory framework created for it by the state or federal government, state agencies have a variety of tools for shaping the availability and nature of services provided through public agencies. For example, state agencies:

- license facilities and other providers;
- license programs and services;
- set rules for reimbursement and fund services;
- establish eligibility criteria for programs;
- establish eligibility criteria for services;
- conduct utilization review;
- provide appeals and due process rights; and
- provide services.

Licensing Facilities and Other Providers

BDS, BMS, BEAS, and the Community Services Center (CSC) (working for both the DHS and BDS) are responsible for licensing the institutional and residential facilities that provide services to people with disabilities. BMS licenses facilities that provide clinical care. BEAS licenses assisted living facilities for adults.² CSC licenses facilities that provide services to children, including some clinical services such as children's residential treatment for both mental health and substance abuse. The licensing unit within the Office of Program Development at BDS licenses all other mental health services for adults and children, including adult mental health and substance abuse residential programs.

The State also licenses agency providers such as home health agencies, and individual providers, such as physicians, speech language pathologists, etc. BMS and BDS license agency providers.³ Individual providers are licensed through licensing boards within the Office of Licensing and Regulation, which is within the Department of Professional and Financial Regulation.

² BMS licenses general hospitals, psychiatric facilities, nursing facilities, intermediate care facilities, mental retardation (ICF-MR). BEAS licenses residential care facilities (RCF), adult family care homes (AFCH), and congregate housing.

³ BMS licenses home health agencies, adult day service programs, and hospice programs. The Office of Program Development in BDS licenses community mental health services for adults and children and substance abuse treatment programs including methadone clinics, Driver Education and Evaluation Programs (DEEP) and Employee Assistance Programs (EAP).

The standards set for facilities and providers can determine the quality and availability of providers. For facilities, the licensing function, for example, includes setting standards for the size or equipment available in the facility, the credentials of the facility staff, record keeping, etc. Licensing standards are also used to shape the nature and availability of alternative settings, including the size of a facility, and the type of care received. For example, the licensing regulations for ICFs-MR declare the State's intent that the ICF-MR should be a homelike setting that allows for meaningful interpersonal relationships.

For individual providers, licensing standards can be used to determine the level and type of training required to provide a specific service. Persons not meeting the specific licensing requirements are barred from entry into the licensed profession.

Licensing Programs and Services

State agencies also license programs and services. Some programs are offered through a licensed facility. For example, the Community Services Center licenses a residential child care facility, and BDS licenses the treatment or program to be provided in the facility and the DOE licenses educational programs offered within residential child care facilities.⁴ A residential care or child care facility with a licensed treatment program is often called a residential treatment facility (RTF).

Other programs or services are offered through non-residential providers. For example, BDS licenses residential and non-residential services for substance abuse treatment and mental health services.

Reimbursement

The State's reimbursement policy establishes who will be reimbursed, how much, and for providing which service (including amount and duration). Some agencies, such as BMS, have established their reimbursement policies by rule. Other programs, such as some of those administered by BDS, establish their reimbursement policies by contract. Some reimbursement rates are standard statewide, others are negotiated and may vary from area to area and agency to agency. The State's reimbursement policy sets standards for quality or credentials that impact the availability of providers, the flexibility of services, and the setting in which services may be provided.

Eligibility Criteria for Programs

Program eligibility criteria determines who is eligible to receive services under a program. In some cases, the State has flexibility in setting eligibility criteria. In other cases, federal law governs eligibility criteria. The impact of program eligibility criteria is described in greater detail in PROGRAM ELIGIBILITY.

Eligibility Criteria for Services

The eligibility criteria for a particular service can be much more specific than the eligibility criteria for the program providing those services. For example, eligibility for a particular service might be tied to a specific need for clinical services or a specific level of functional capacity. Generally, clinical or functional need for a service is determined during an assessment process

⁴ DOE Rule, 05-071 CMR Chapter 18.

and might be determined to change during a reassessment. In some cases, a change in the level of need can lead to a shift in where a person lives. For example, if a person living at home with in-home support crosses a certain threshold for level of medical need and that person is not eligible to receive more in-home services, then that person may have to move to a nursing facility to receive more services.

Utilization Review

Utilization review is the evaluation of the necessity, appropriateness, and efficiency of the use of services, procedures, or facilities. Utilization review can include prior authorization of services or a review of the appropriateness of admissions, services ordered and provided, and discharge practices. A number of MaineCare services are subject to periodic utilization review.

Appeals and Due Process

Each state agency must provide individuals the right to appeal an agency decision and a fair process for appealing the decision. Many state agency decisions are subject to review by a state or federal court, if the state agency refuses to change its decision during the state agency's appeal process.

Providing Services

The State is a direct provider of services to persons with disabilities. For example, the State provides hospital services through the Augusta Mental Health Institute, the Bangor Mental Health Institute, and through state-owned intermediate care facilities for persons with mental retardation. In addition, the State provides service coordination through caseworkers employed by the Bureau of Child and Family Services, the Bureau of Elder and Adult Services, the Department of Behavioral and Developmental Services, the Bureau of Rehabilitation Services, and through probation officers employed by the Department of Corrections. The State provides protective services through BCFS for children and BEAS and BDS for adults. The State provides services to persons in its correctional facilities. The State also provides educational services through the Governor Baxter School for the Deaf and in unorganized territories.

Role of the Departments

Many state agencies play a role in providing home and community based services. The role of these departments are briefly described here:

- Department of Behavioral and Developmental Services (BDS);
- Department of Corrections (DOC);
- Department of Education (DOE);
- Department of Human Services (DHS); and
- Department of Labor (DOL).

Other state agencies are described in the HOUSING, TRANSPORTATION and EMPLOYMENT sections.

Department of Behavioral and Developmental Services (BDS)

BDS is responsible for services for people with mental illness, mental retardation, developmental disabilities, and addiction disorders for children and adults. BDS is organized into two main divisions for serving adults and children with mental illness and mental retardation, with the Office of Substance Abuse (OSA), the Office of Consumer Affairs, and the Office of Program Development organized separately. The two divisions, the Division of Administrative Services and the Division of Systems Operations, are organized by functions and by category of need. The Division of Administrative Services responsibilities include finance, information systems, MaineCare and managed care. The Division of Systems Operations organizes the delivery of services into three regions and the institutions operated by BDS.

BDS' three regions comprise seven local service networks. Regional office staff both provide services or contract with or otherwise arrange for services to be delivered through private providers. Regional office staff also link consumers with other private and public services. OSA is integrating its services into BDS' regional offices.

Table 2. 3 BDS Regions

| Region | Local Service Network | County |
|-------------------|------------------------------|---|
| Region I | Cumberland | Cumberland |
| | York | York |
| Region II | Kennebec-Somerset | Kennebec, Somerset |
| | Coastal | Knox, Lincoln, Sagadahoc, Waldo |
| | Western | Androscoggin, Franklin, Oxford |
| Region III | Aroostook | Aroostook |
| | Northeast | Hancock, Penobscot, Piscataquis, Washington |

Adults with Mental Illness. Through BDS, adults with severe and disabling mental illness have access to a range of services. These services include service coordination, crisis intervention, residential and housing support, rehabilitation, and outpatient services. BDS provides almost all community mental health services through contracted providers. Adults with mental illness are served in institutional settings, including state-operated and private psychiatric facilities, and residential treatment facilities. In addition, BDS serves people living in foster homes, their own homes, in group homes, in shelters, and on the street.

Adults with Mental Retardation and Autism. BDS is responsible for providing an array of supports and services to adults with mental retardation and autism. Supports and services are provided through a network of community providers including: residential supports, day habilitation, supported employment, transportation, professional services, respite, environmental modifications, and adaptive aids. The majority of people with mental retardation or autism are

supported in small community settings. BDS provides services to individuals who live with their families or live in their own homes or apartments. Services are also provided to individuals who live in assisted living facilities, intermediate care facilities (ICF/MR) and in nursing facilities. Services provided by state employees include service coordination, guardianship, representative payee, adult protective and crisis services. The state operates two ICF/MR group facilities, Aroostook Residential Center for 12 people and Freeport Towne Square supporting 12 people in two homes.

Children with Mental Health and Developmental Needs. BDS is responsible for providing services to children with mental illness, mental retardation, autism, and developmental delays. These services are provided through many of the same mechanisms available for adults and there is overlap in the types of services provided to children and adults. In addition, services for children are coordinated with educational services provided through school systems. Parents (or guardians) also play an important role in delivery of services to children. BDS operates Elizabeth Levinson Center, an ICF-MR nursing facility for children.

Persons with Addiction Disorders. BDS also funds substance abuse treatment services. BDS licenses private substance abuse treatment programs and contracts with many of these providers. Services include detoxification, residential rehabilitation, extended shelter, shelter, halfway house, intensive outpatient program, extended care, outpatient care, driver education, and correctional services. Services are provided to persons located in psychiatric and general hospitals, residential treatment facilities, correctional facilities, halfway houses, shelters, at home, or on the street.

Department of Corrections (DOC)

DOC is responsible for operating the State's adult and juvenile correctional facilities and programs. A person in the correctional system may or may not have a disability. However, mental illness, addiction disorders, learning disabilities, mental retardation and other disabilities are frequently encountered among people in the correctional system.

The mission of DOC is to hold the offender accountable to the victim and to the community and to prevent crimes and reduce the likelihood of juvenile and adult offenders re-offending. In order to achieve its mission, DOC must serve a number of roles. First, it is an executive agency charged with carrying out sentences issued by courts upon conviction of criminal offenses. DOC takes physical custody of sentenced offenders ordered to serve a term of incarceration. DOC also assumes responsibility for offenders sentenced to probation, providing supervision and monitoring compliance with conditions ordered by the court. DOC serves a public safety function by separating convicted offenders from the public as well as maintaining the safety of inmates, juvenile residents, staff and others present at facilities. DOC is a treatment provider, both under constitutional and legislative mandates requiring health care and treatment for those in physical custody, as well as assisting in rehabilitation and recovery for inmates and probationers. The Department works to rehabilitate offenders by providing educational, training and work programs. This function benefits individual offenders and the public by helping to prevent and reduce recidivism.

DOC operates six facilities for incarcerated adults. The facilities are of varying security level and size. The Maine Correctional Center serves as the primary intake facility for the adult custodial correctional system. It is also the facility in which inmates with special needs, including serious medical conditions and disabilities, are placed. DOC also operates two custodial facilities for juveniles. The Long Creek Youth Development Center in South Portland and the Mountain View Youth Development Center in Charleston offer educational and treatment programs for youths committed to DOC's custody.

DOC also operates a pre-release program in Hallowell. Pre-release is a transitional program for people who are near completion of their sentence. The pre-release program is intended to gradually re-integrate offenders into the community through work, counseling and treatment.

DOC operates its probation system through four adult and juvenile regional community corrections offices located in Bangor, Augusta, Lewiston-Auburn and Portland. Probation involves a suspended term of incarceration. An offender sentenced to DOC will serve one of the following three types of sentences: incarceration only; probation only; or to a split sentence which commences with a term of incarceration followed by a term on probation. In order to avoid imposition of the suspended term of imprisonment, a person must comply with the conditions of probation imposed by the sentencing court. In many cases, the conditions of probation include participation in substance abuse and mental health counseling and treatment.

Department of Education (DOE)

DOE, through the Special Services Team, is responsible for overseeing the implementation of the Individuals with Disabilities Education Act (IDEA) among the school systems in Maine. DOE provides early intervention services for pre-school children (0 to 5); and special education services for school-aged children (5 to 20).

These services are provided to children with any of a range of disabilities that DOE categorizes as mental retardation, hearing impairment, deafness, speech or language impairment, blindness or a visual impairment, emotional disability, orthopedic impairment, other health impairment, learning disability, deaf-blindness, multiple disabilities, developmental delay, traumatic brain injury, autism, and specific learning disabilities.⁵

Special education services are provided through a variety of classroom placements and supportive services which include therapies, counseling, training, transportation, assistive technology and numerous other services designed to make education accessible. The majority of services are delivered to children in non-residential school settings. However, for some children, services can be delivered in either in- or out-of-state residential placements.

Early intervention services are provided through one of 16 regional Child Development Services agencies. These agencies also provide therapies, counseling, treatments, care coordination and other services designed to enhance the development of children who are or are at risk for disabilities, and to provide support to families. Child Development Services are governed by regional boards.

⁵ DOE Rule, 05-071 CMR Chapter 101 and 180.

Individual school administrative units (SAU) are responsible for administering special education services. A school administrative unit can be a single town, or in many cases, more than one town or municipality combined. The SAU then has responsibility for special education services within the combined communities. SAUs are governed by school boards or committees elected by participating communities. Some SAUs have organized regional boards responsible for operating regional programs to assist in meeting their special education responsibilities. There are 285 SAUs in Maine, comprising 492 municipalities.

The DOE also oversees adult and vocational education services, including adult education for persons with disabilities. Instructional services might include teaching basic skills through practical life coping instruction and vocational instruction relevant to individual goals and needs. Adult education might be provided to persons in correctional facilities.

Department of Human Services (DHS)

DHS is organized into three regions with several offices in each region.

Table 3. 3 DHS Regions

| Region | Offices | Counties |
|-------------------|---|---|
| Region I | Portland, Biddeford, Sanford | Cumberland, York |
| Region II | Lewiston, Farmington, Augusta, Rockland, Skowhegan, South Paris | Kennebec, Somerset, Knox, Lincoln, Sagadahoc, Waldo, Androscoggin, Franklin, Oxford |
| Region III | Bangor, Ellsworth, Machias Calais, Houlton, Caribou, Fort Kent | Aroostook, Hancock, Penobscot, Piscataquis, Washington |

Within the Department of Human Services, several bureaus play an important role in providing services to people with disabilities. These bureaus include the:

- Bureau of Child and Family Services;
- Bureau of Elder and Adult Services;
- Bureau of Family Independence;
- Bureau of Health; and
- Bureau of Medical Services.

Bureau of Child and Family Services (BCFS). BCFS is responsible for protecting and assisting abused and neglected children, and children in circumstances that present a risk of abuse and neglect, and their families.⁶ Although children in protective custody may or may not have a disability, there is a higher prevalence of health problems for children in protective custody than children in the general population. These health problems include chronic medical conditions, physical impairments, mental health problems, and developmental disabilities. Children in

⁶ 22 M.R.S.A. § 4003.

BCFS' care may be in a residential child care facility, a correctional facility, a therapeutic or treatment level foster home, a regular foster home, a pre-adoption home, a shelter, on the street, on their own, in an independent living arrangement, or in their family home.

BCFS is responsible for providing services to the children in its custody. These services are designed to meet the child's assessed educational, developmental, health and mental health, social and permanency needs. BCFS pays for these services if the child is not already covered by another insurer, including MaineCare, or if the services are not already provided through another department.

Bureau of Elder and Adult Services (BEAS). BEAS advocates on behalf of Maine's elderly and is involved in establishing direction and policies for programs that serve older people. BEAS programs provide a range of home and community based services for older people and adults with disabilities. BEAS also administers Maine's Adult Protective Services, including the conservatorship and guardianship programs; disability determination services for the Social Security Administration; the Assisted Living Program, which licenses and inspects assisted living programs, including residential care facilities; the Adult Family Care Home Program; the Long-Term Care Pre-Admission Assessment Program; and the Certificate of Need Process for Nursing Facilities. BEAS also administers federal Older Americans Act funds, which are allocated to Maine's five area agencies on aging to provide services such as meals, information and referral, outreach, benefits and health insurance counseling, congregate housing and assisted living, and respite care. The area agencies also support other services such as legal assistance and transportation. Long-term in-home services are available through the state-funded Home Based Care program and MaineCare waiver services for elders and adults with disabilities. These services are provided through contracts with community agencies and include assessment and care planning, care coordination, and in-home services such as homemaker, personal care, and nursing services.

Bureau of Family Independence (BFI). BFI administers income support programs. BFI is responsible for defining and determining income eligibility for the MaineCare program. In addition, BFI determines eligibility for Temporary Assistance for Needy Families (TANF); Additional Support for People in Retraining and Employment (ASPIRE), a job preparation program for persons receiving TANF; food stamps; general assistance and emergency assistance.

Bureau of Health (BOH). Within BOH, the Division of Maternal and Child Health administers the Coordinated Care Services for Children with Special Health Needs program. The CCS/CSHN program is responsible for enhancing the provision of and access to health services for children with special health needs, including children with congenital or acquired chronic disease, condition and/or physical disability. The CCS/CSHN program pays for major subspecialty medical care, including diagnostic, medical, surgical, corrective and therapeutic intervention for children with special health needs ages birth to eighteen when income eligible and other financial resources are not available.

Bureau of Medical Services (BMS). The Department of Human Services is Maine's designated single state Medicaid agency. BMS has responsibility for defining and paying for the services provided under the Medicaid program, now called MaineCare, within parameters set by the

federal government. BMS is also responsible for defining specific medical eligibility for those services. MaineCare is the state and federal partnership that pays for medical and long-term care services for people who meet the eligibility criteria for low income or medical need. BMS sets policy for MaineCare services, pays claims, and monitors the quality of service and providers.

Department of Labor (DOL)

DOL, through the Bureau of Rehabilitation Services (BRS), offers several programs to persons with disabilities.

BRS offers two vocational rehabilitation services, one for all persons with disabilities and another program for people who are blind or visually impaired. Vocational rehabilitation services include counseling, training and educational opportunities, home modifications, adaptive and assistive devices, job coaching, and other services to assist people in gaining or maintaining employment. For persons requiring support services extending beyond completion of the vocational rehabilitation program, either BRS and BDS will fund extended support services. DOL vocational rehabilitation services are provided through CareerCenters located in 23 communities in Maine.⁷

BRS administers the self-directed personal care services, funded under the Medicaid state plan, a Medicaid waiver, and through the state general fund. Self-directed personal care services are accessed through Alpha One.

BRS administers two Independent Living Services programs. The Independent Living Program provided through AlphaOne, and the Independent Living Program for Individuals who are Blind provided through the Iris Network, offer services that help a person to function independently, including counseling services, housing and home modification, adaptive devices and technology, etc.

BRS also designates Maine's Independent Living Centers. Currently Maine has one Independent Living Center, AlphaOne.

BRS administers the Telecommunications Devices Program, which provides telecommunications equipment to persons who are deaf or hard of hearing through a lending or cost-sharing program. BRS also administers the Education Services for Blind and Visually Impaired Children program, which provides instructional and counseling services to school children and their families.

⁷ CareerCenters are located in Augusta, Bangor, Bath, Belfast, Calais, Dover-Foxcroft, East Wilton, Ellsworth, Houlton, Lewiston, Machias, Madawaska, Millinocket, Newcastle, Norway, Portland, Presque Isle, Rockland, Rumford, Sanford, Saco, Skowhegan, and Waterville.

The Role of the Federal Government

Many state programs are the product of federal law. For the most part, the federal government influences state services through funding and through civil rights laws.

The federal government has enacted several civil rights statutes, such as the Americans with Disabilities Act, which govern the states' responsibilities and individual rights under programs, whether or not funded with federal dollars.

Key federal statutes providing civil right protections to persons with disabilities include:

- Americans with Disabilities Act (enforced by eight federal agencies);
- Civil Rights of Institutionalized Persons Act (enforced by the Department of Justice);
- Fair Housing Act (enforced by the Department of Housing and Urban Development);
- Rehabilitation Act of 1973 (federal agencies enforce within own programs); and
- Individuals with Disabilities Education Act (IDEA).

Once federal funding is accepted, states are required to comply with federal law tied to the federal dollars. For example, a state may or may not choose to participate in the MaineCare program, but, once having decided to participate, the state must comply with federal requirements. Sources of federal funding are discussed in more detail under FUNDING STREAMS.

The following summarizes the role of a number of federal agencies.

Table 4. Roles of Federal Agencies

| Federal Department | Influence on State Programs |
|---|---|
| Department of Education | |
| Office of Civil Rights (OCR) | OCR enforces Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act in education programs and activities that receive Federal financial assistance (including state education agencies, elementary and secondary school systems, post-secondary schools, state vocational rehabilitation agencies, etc.). |
| Office of Special Education and Rehabilitation Services (OSERS) | Houses: (1) the Office of Special Education Programs which provides funding, rules, oversight, and technical assistance for special education services under Individuals with Disabilities Education Act (IDEA); and (2) the Rehabilitation Services Administration which administers the Rehabilitation Services Act (vocational rehabilitation funds; protection and advocacy funds, etc., funding for centers for independent living). |

| | |
|--|---|
| Department of Health & Human Services | |
| Administration on Aging (AoA) | Administers programs under the Older Americans Act of 1965, including funding for supportive in-home and community services and local Area Agencies on Aging. |
| Administration for Children and Families | Houses the Administration on Developmental Disabilities, which funds developmental disability councils, the protection and advocacy agencies, and university centers for excellence; and the Children's Bureau, which assists states in the delivery of child welfare services. |
| Centers for Medicare and Medicaid Care Services (CMS) | Administers the Medicaid and Medicare programs. Provides federal match funding for Medicaid; sets standards for Medicaid and Medicare programs, including covered services, eligibility criteria, provider types. |
| Health Resources and Services Administration (HRSA) | Houses the Division of Services for Children with Special Health Needs (within the Maternal and Child Bureau) which develops and implements programs to integrate services for children with special health care needs. |
| Office of Civil Rights (OCR) | Enforcement of civil rights statutes (including the ADA) to prevent unlawful discrimination in provision of services through HHS. |
| Substance Abuse & Mental Health Services Administration (SAMHSA) | Houses Center for Mental Health Services, Center for Substance Abuse Prevention, and the Center for Substance Abuse Treatment, all of which provide grant funding for services and systems improvement, and protection and advocacy agencies. |
| Department of Housing and Urban Development | |
| Office of Fair Housing and Equal Opportunity | Investigates discrimination complaints under the Fair Housing Act, ADA, etc |
| Office of Housing | Administers affordable housing programs such as Section 8; Section 811, Supportive Housing for Persons with Disabilities; and Section 202, Supportive Housing for the Elderly. Enforces Fair Housing Act. |
| Department of Justice | |
| Civil Rights Division | Enforces Americans with Disabilities Act against state and local governments and private parties. |

| | |
|---|--|
| Department of Justice (cont'd) | |
| Office of Justice Programs | Administers formula grants awarded to state governments; houses Office of Juvenile Justice and Delinquency Programs and other programs related to law enforcement, corrections, etc. |
| Department of Labor | |
| Employment & Training Administration | Administers Workforce Investment Act. |
| Department of Transportation | |
| Federal Highway Administration | Responds to complaints about the design of or accessibility related to highways including curb cuts, pedestrian crosswalks, interstate and highway restroom facilities, parking spaces, parking lots, etc. |
| Federal Transit Administration | Responds to complaints concerning the implementation and operation of fixed rail and bus (including paratransit) systems. |
| Office of the Secretary, Consumer Affairs | Enforces access to airplanes and airports. |
| Social Security Administration (SSA) | |
| Office of Disability | Administers the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) programs, which triggers eligibility for MaineCare (Maine's Medicaid program). |
| Office of Employment Support Programs | Administers Ticket to Work and Work Incentive Improvement Act. |

Health, Mental Health and Supportive Services

Funding Streams

The funding source establishes the constraints governing a program. Some constraints are legal and regulatory constraints. For example, the MaineCare program and IDEA, both discussed below, establish parameters within which the State must operate. Other constraints are financial. For example, if the financial burden is shared with the federal government, rather than carried by the state (or schools), the State's decision about how much to spend might be different. This section reviews some of the differences between funding streams and some of the ways the funding stream influences the State's authority and flexibility, individual rights under different programs, and the coherence of services across programs.

The MaineCare Program

The MaineCare program, formerly known as the Medicaid program,⁸ overlays many state programs. While MaineCare does not target persons with disabilities, it provides health coverage for many people who have a disability and the State funds many of its services to people with disabilities through the MaineCare program. In fiscal year 2001, the State paid over \$1.3 billion for MaineCare services and served over 184,000 people. The federal government pays 66% and Maine pays 34% of the cost of MaineCare services. Among the more than 184,000 people served by MaineCare, 7,000 are children with disabilities, 53,000 are eligible based on an SSI disability determination, and 25,000 are elderly (SFY 2001).

The MaineCare program includes two primary components relevant to this document: MaineCare state plan services and MaineCare waivers for home and community based services.

State Plan Services. The federal government, through the Centers for Medicare and Medicaid Services (CMS),⁹ sets certain parameters for which services are covered, what eligibility criteria are applied, and other features of the MaineCare program. Within those parameters, Maine has a certain amount of flexibility to tailor the MaineCare program to meet the needs of Maine people.

State plan services are those services a state offers to everybody who meets the eligibility criteria. Services included under the state plan are an "entitlement," meaning that, once offered, a state must provide them to all persons meeting its eligibility criteria, regardless of available funding.¹⁰ A state must have a state plan, approved by CMS, describing these services and other required information.

- Services: The federal government requires each state to offer certain mandatory services through its Medicaid program. In addition, Maine has chosen to offer almost every

⁸ MaineCare is the new name for several of Maine's publicly funded health care programs, including Medicaid state plan services and Medicaid waiver services, both discussed here, and Cub Care, a program expanding health care coverage for children.

⁹ Formerly the Health Care Financing Administration, or HCFA.

¹⁰ "Entitlement" to a service is different from "eligibility" for a service. A person eligible for MaineCare must also meet other criteria (e.g., level of need) in order to receive certain services.

optional service allowed under Medicaid. (Many consider Maine’s MaineCare package to be “rich” in the sense that it covers many services.)

Maine has a significant amount of flexibility to determine the scope of each service. For example, some states limit the number of physician office visits paid for each year. For many services, Maine has set no limitations other than medical necessity. For others, services might be limited by who can provide them, what can be provided, where they can be provided and how much they cost.

The scope of services for children is especially broad. No children’s services are limited other than by medical necessity. Under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services, a medically necessary service can be covered even if it is not otherwise available under MaineCare.¹¹

- Eligibility: Eligibility for MaineCare is based on income and assets. The income and asset tests vary by age group and whether or not a person has a disability or is found to be “medically needy.” The table below summarizes the eligibility criteria for specific groups of people covered under MaineCare.¹²

In addition to these eligible groups, other financial eligibility rules apply for persons residing in nursing facilities or residential care facilities. In addition, a person may be found to be “medically needy” if they incur medical expenses in excess of a MaineCare determined “deductible.”¹³ A person who meets the financial eligibility criteria set by the State is entitled to those services; a state may not limit services because of a shortage of funds. The State can limit the services offered to eligible persons or the reimbursement rate for providers.

Once a person meets the financial eligibility criteria, that person is eligible for most services. However, some services also have specific eligibility criteria. These criteria might relate to the person’s age, the setting in which the person resides or would otherwise reside (*e.g.*, a nursing facility or home), or the person’s medical need for the services. In some cases, a medical provider must make a finding of a specific medical condition or that specific services are needed before a person is eligible to receive certain services. Even after determined eligible for a service, some services are reviewed for medical necessity before a person can receive the service.

The table below summarizes the eligibility criteria for the relevant eligibility categories. The table omits significant detail about what is counted or disregarded as income or assets for the purposes of eligibility.

¹¹ Maine Medical Assistance Manual, DHS Rule, 10-144 CMR Chapter 101, Chapter V, Section 2.

¹² This table does not include all eligibility categories, only those relevant to persons with a disability.

¹³ To determine the “deductible” \$315 is subtracted from an individual’s monthly income. The “deductible” equals this amount times six. A person pays all medical expenses incurred over a six month period up to this deductible. Once the deductible is met, MaineCare pays the rest. At the end of the six month period, this process starts over again.

Table 5. MaineCare State Plan Financial Eligibility Criteria

| Age Group | Income Limit | Asset Limit | Other criteria/notes |
|--------------|---------------------------|------------------------------|---|
| 0 to 1 | 185% of FPL ¹⁴ | none | Parents' income is counted. |
| 1 to 18 | 150% of FPL | none | Parents' income is counted. |
| 1 to 18 | 200% of FPL | none | Parents' income is counted. Parents pay monthly premium. |
| 0 to 18 | \$1,635 | \$2000 | If child is living in the community and has a severely disabling condition requiring institutional level care and meets SSI criteria for disability, then parental income and assets are not counted. This eligibility category is known as "Katie Beckett" eligibility. |
| 19 to 20 | 100% of FPL | \$2000 | Parents' income and assets are counted if living with parents. |
| 21 to 64 | 100% of FPL | \$2000 single, \$3000 couple | Person must: <ul style="list-style-type: none"> • meet SSI definition for disabled or blind;¹⁵ • be a single parent; or • be part of two family with one parent working less than 130 hours or unable to work for at least 30 days. |
| 65 and older | 100% of FPL | \$2000 single, \$3000 couple | |
| 21 to 65 | 100% FPL | \$2000 single, \$3000 couple | Not otherwise eligible, e.g., childless adults. |

Home and Community Based Service Waivers. States may apply for a home and community based service waiver that provides different services under different rules than allowed under the state plan. For example, under Maine's waivers, certain community-based services are covered that are not allowed under the state plan, the income and asset tests are changed, and the number of people that can be served under the waiver is limited by available funding, even if more people are eligible for waiver services.

Waivers are initially approved for three years and may be renewed at five-year intervals. A state must document that there are safeguards in place to protect the health and welfare of beneficiaries. Every year, a state must demonstrate to CMS that the cost of providing the home and community waiver services does not exceed the average cost of care for the people served in

¹⁴ FPL stands for federal poverty levels established by the U.S. Department of Health and Human Services as guidelines for determining program eligibility.

¹⁵ "SSI" is the Supplemental Security Income program which provides income support to persons with disabilities or who are blind. Under SSI a "disability" must be a physical or mental impairment that substantially impairs a person's ability to work, and must have existed or be expected to continue for one year.

an institution. By federal law, eligibility for the home and community based waiver services is limited to only those whose needs require institutional level services.¹⁶

Maine has four home and community based waivers with the shortened titles of:

- Adults with Disabilities;¹⁷
- Elderly;¹⁸
- Persons with Mental Retardation;¹⁹ and
- Physically Disabled.²⁰

The first three waivers offer a full range of home and community services. The last waiver offers self-directed personal care services and service coordination to persons with physical disabilities. BMS worked with the Department of Behavioral and Developmental Services to develop the waiver for persons with mental retardation and with the Bureau of Elder and Adult Services (BEAS) to develop two other waivers and is now working with the Bureau of Rehabilitation Services (BRS) to transfer the Physically Disabled Waiver from BEAS to BRS.²¹

The following table shows the financial eligibility criteria applied for waiver services. The table omits significant detail about what is counted or disregarded as income or assets for the purposes of eligibility.

¹⁶ The waiver programs for adults with disabilities and elders also limit eligibility for waiver services to those for whom the projected cost of home and community services is not estimated to exceed 75% of the average cost of nursing facility services.

¹⁷ Maine Medical Assistance Manual, DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 18.

¹⁸ Ibid, Section 19.

¹⁹ Ibid, Section 21.

²⁰ Ibid, Section 22.

²¹ Legislation has been introduced to transfer administration of all self-directed programs (MaineCare state plan, MaineCare waiver and state-funded) from BEAS to BRS. If this transfer occurs, BMS will also be working with BRS.

Table 6. MaineCare Waiver Eligibility

| Waiver | Age Group | Income | Asset | Other |
|--|------------------|---------------|---|---|
| Adults with Disabilities | 18 to 59 | \$1,635 | \$2000 (\$3000 for couple; many assets not counted) | Eligible for nursing facility care. |
| Elderly | 60 to 64 | | | Person must meet SSI definition of blind or disabled; ²² or be eligible for nursing facility care. |
| | 65 and older | | | Eligible for nursing facility care. |
| Persons with Mental Retardation | All ages | | | Person must be eligible for care in an intermediate care facility for persons with mental retardation. |
| Physically Disabled | 18 and older | | | Person must have disability; or be eligible for nursing facility care. |

Budget and Maximization. Maine has worked to maximize the contribution of federal dollars to all health services the State provides. Using this strategy, if another state agency provides a service to someone eligible for MaineCare, and the service is covered under the MaineCare program, the service can be paid for through MaineCare. In this way, the state pays only 34% of the service cost, while the federal government pays 66%.

Under this approach, BMS has developed funding agreements with other state agencies. Under these arrangements the other state agency takes responsibility for authorizing and administering a specified set of services. In some cases, the other agency also has responsibility for funding the State's share of the cost for those services. The State's share is often called the "state seed." The state seed is obtained through the legislative budget process or through local funding. In some cases, BMS provides the State's share for services administered by another agency.

BMS works with the other agencies as necessary to prepare the policies, establish medical eligibility criteria, set rates, and develop waivers. The Department of Behavioral and Developmental Services and the Department of Labor are the only departments other than DHS with statutory authority and a line item in the budget for providing State seed for MaineCare services.²³

²² "SSI" is the Supplemental Security Income program which provides income support to persons with disabilities or who are blind. Under SSI a "disability" must be a physical or mental impairment that substantially impairs a person's ability to work, and must have existed or be expected to continue for one year.

²³ The transfer of the self-directed programs to BRS may mean that BRS will also provide seed for MaineCare services.

For the purposes of this document, the other agency is said to “administer” the MaineCare funded services. These administering functions include quality oversight, managing and overseeing contracted providers, responding to appeals, etc.

Special Education

Until the mid-1970s, children with disabilities could be denied access to the public education available to the general population. The historic practice of excluding children with disabilities from schools reinforced segregation, making children with disabilities “invisible” within their communities. Excluded from schools, children with disabilities were often not prepared for independent adulthood, fulfilling society’s expectation that a disability is a condemnation to dependence and isolation.

Beginning in 1975, and currently enacted as the Individuals with Disabilities Education Act (IDEA), federal law has required states to provide early intervention and educational services to children with disabilities. Under IDEA, state and local schools must provide equal access to a “free appropriate public education” (FAPE) to all children with a disability. FAPE is to be provided in the “least restrictive educational alternative,” meaning that a child is to be educated in the regular classroom unless it is determined and documented that the child’s education can only be achieved in another setting.

IDEA has served as an important tool in fulfilling the vision of integration. The presumption that a child will be included in the regular classroom means that children with disabilities are no longer to be isolated and no longer to be invisible. The emphasis on early intervention has meant many children receive the services they need in time to maximize their independence and avoid unnecessary dependence (and possibly institutionalization).

As a federal mandate, IDEA imposes a series of requirements on states and local communities. Schools are required to offer a continuum of alternative special education placements and a range of special and supportive education services. A child can receive supportive special education services if the child’s disability adversely affects the child’s educational performance.²⁴ Special education and related services are available to all children determined to require them, regardless of income level. As with MaineCare, services under IDEA are an entitlement -- once it is determined that a child requires special education and related services in order to access FAPE, that child is entitled to receive services and the services must be provided. The cost of the services and the availability of funding are not acceptable reasons to deny services. Because services under the IDEA are an entitlement, there can be no waiting list for services.²⁵

Services provided under IDEA are funded through three funding streams²⁶ In 2001, the federal government contributed approximately 10 percent. Another 51% was contributed through the State’s general fund and local schools contributed the remaining 39 percent. In actual dollars, the three funding sources contributed:

²⁴ DOE Rule, 05-171 CMR Chapter 101, Section 3. For more discussion of special education services see THE ROLE OF STATE GOVERNMENT above, and HOME AND COMMUNITY SERVICES below.

²⁵ Although there are no official waiting lists, there is unmet need due to provider shortages.

²⁶ Special Education Costs data contributed by John Kierstead, Maine Department of Education.

| Funding Source | Amount |
|-----------------------|----------------------|
| Federal Government | \$25,125,639 |
| State Government | \$123,308,709 |
| Local Schools | \$94,780,767 |
| TOTAL | \$243,215,115 |

Other Federal Funds

In addition to MaineCare and IDEA, federal funds come into Maine through a variety of other sources. Below is a list of some of the major sources of federal funds administered by Maine agencies.

| | |
|------------|--|
| BDS | SAMHSA distributes funds through a Substance Abuse Prevention and Treatment grant (\$6,468,750) and Community Mental Health Services (\$1,832,700) block grants; Projects for Assistance in Transition from Homelessness (\$300,000); and other discretionary funding. ²⁷ A portion of funding from the Social Services Block Grant helps to pay for mental retardation services. |
| DOC | The Office of Justice Programs within the Department of Justice awards formula grants to the Department of Corrections and other state agencies (including the Department of Public Safety). |
| DOE | In addition to special education services for children 5 to 20 under IDEA, the Office of Special Education Programs distributes IDEA funding for early intervention services through two other formula grant programs. These include the Preschool Grants program (Part B, § 619 under IDEA) for children ages 3 through 5 (\$2,567,160); and the Grants for Infants and Families program (Part C of IDEA) for infants and toddlers, ages birth through 2 and their families (\$2,043,290). ²⁸ |
| DHS | <p>The Bureau of Child and Family Services receives funding for child welfare, foster care, adoption assistance, etc., through the Administration for Children and Families.</p> <p>The Bureau of Elder and Adult Services receives funding through the Administration on Aging for local area agencies on aging, nutrition services, in-home supports, benefits counseling, and other supportive services. BEAS also receives funding for the Meals on Wheels program under the Social Services Block Grant, allocated through the Community Services Center.</p> |

²⁷ Grant amounts for Fiscal Year 2001/2002.

²⁸ Appropriations for Fiscal Year 2002.

The Coordinated Care Services for Children with Special Health Needs program administered through the Bureau of Health is funded through Maine's Maternal and Child Health Bureau and the Title V Maternal and Child Health Block Grant.

DOL

The federal Rehabilitation Services Administration distributes funding for vocational rehabilitation services (\$13,895,960), independent living services (\$297,580), independent living services for persons who are blind (\$225,000), and supported employment (\$300,000).²⁹ Federal regulations govern prioritization and eligibility for vocational rehabilitation services as well as the duration of federally funded vocational. The Maine Bureau of Rehabilitation Services (BRS) receives payment from the Social Security Administration when BRS successfully assists a person in finding employment and no longer relies on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). DOL receives funding from other programs under the Workforce Investment Act, not necessarily related to serving persons with disabilities but which can benefit persons with disabilities.

State General Fund

Annually, the State General Fund provides both the State's share or "match" used to draw down federal funds for federal programs. In addition, the State supports a number of programs paid for solely with state funds.

As a general rule, the State has discretion about how to spend general fund money for state programs not governed by federal law.³⁰ That means that the State can determine who is eligible and what services should be provided. As a general rule, services funded under the general fund are not subject to financial eligibility criteria, although financial status is often used to determine the level of cost-sharing.

State-funded programs are not entitlement programs, meaning that many people may be eligible to receive services but, if funding is not available, not all can receive services. That means that many people might be on waiting lists, waiting for funds or providers to become available. Although state-funded programs offer the State the most control and flexibility in designing services, state-funded services are more vulnerable to competing state budgetary priorities, and an identified need for funding is not always met.

The Bureau of Elder and Adult Services and the Department of Behavioral and Developmental Services both administer several state-funded programs, including home based care for adults and children with mental illness and elders and adults with physical disabilities. The Bureau of Rehabilitation Services administers state funding for the Maine Center on Deafness and educational services for children who are blind or visually impaired.

²⁹ Appropriations for Fiscal Year 2002.

³⁰ It should be noted that the ADA is a federal law that, at least indirectly, governs how states spend their money, although it does not govern a particular program or service for people with disabilities.

Relationship Between Funding Streams

Funding streams influence the type and scope of services available. Some financial resources are private, provided by businesses, industries, fraternal organizations, religious groups, private individuals and community groups. In general private funding sources establish the eligibility guidelines and set the scope, type, and amount of services available. The remaining resources necessary for the service delivery systems come from a combination of local, state and federal governments. The purpose of the local, state, and federal levels of funding is to provide resources to communities and individuals. These public resources may be in the form of direct services or funding to support programs and services.

Most of the larger funding streams (MaineCare, Special Education and Vocational Rehabilitation) represent cooperative federalism. Simply put, the federal and state governments share responsibilities for providing services. The federal government sets the general program criteria and provides financial assistance to the states. The states administer the programs and supply part of the program's costs. Federal entitlement programs like MaineCare and Special Education offer more services and the State is legally obligated to provide the services to all eligible individuals. State-funded services and some federal/state programs such as Vocational Rehabilitation are considered to be eligibility programs. In an eligibility program, funding can be more limited in range and scope. Services can be denied if funding is not available, services are delivered based on available funding, and waiting lists are common.

While the local, state, and federal levels of the service delivery systems are furthest away from the direct contact with individuals and families, they play a major role in determining the types and amounts of services available. The decisions made by individuals and their families are often determined by the structure of the system itself and not by individual preferences and beliefs. Complex systems of care are organized into various agencies and programs that have specific roles in developing, establishing and delivering resources to individuals and their families. Each agency and program is responsible for carrying out a specific function in the overall systems design and operation. These agencies function independently; this independence often creates barriers that prevent coordination between services, programs and agencies. Some of the most common barriers are:

- disagreements about how certain policies should be implemented;
- focusing only on the role of one's own agency or program rather than seeing it as a part of the whole system;
- inability to share or integrate information across programs; and
- lack of information and understanding about the role and function of other agencies and programs.

The individuals who work in the service delivery system carry out the mission of a specific program or agency. These individuals are concerned about doing their particular job and they must perform their job responsibilities within the prescribed mandates, policies and procedures. These system issues result in inconsistencies for the individual consumer and his or her family. The inconsistencies between funding streams are apparent to those transitioning from one funding stream to another and to those who receive funding under multiple funding streams. Examples of some of the problems include:

Transitioning Across Age Groups. A child receiving children’s services funded under MaineCare and special education is “entitled” to those services if eligible and cannot be denied because of lack of funding. Many people transitioning to adult services transition to non-entitlement programs, finding that their access to services is limited, there are fewer types of services available, and the funding for services is less. Many people go from receiving services to being denied services or waiting for them.

Transitioning Across Income Eligibility Thresholds. A person with the same level of need may change income eligibility status, losing eligibility for MaineCare but maintaining eligibility for state-funded services. That person may have the same need for services, and the same inability to pay for services, but is unable to receive them because state funding is not available.

Patched Together Services. In some cases, a person can get funding for multiple “packages” of services funded through different funding streams. Sometimes, these packages of services will overlap, sometimes there will be gaps between them. Providers do not have the capacity to blend the funding streams to make one comprehensive package of services tailored to the needs of the individual or family.

For more discussion of the interrelationship between funding streams see the report FLEXIBLE FUNDING TO PROMOTE INTEGRATED SERVICES AND CHOICE AND CONTROL.

Entry into the Service Systems

People might enroll in publicly funded programs at any point in their lives. A child might be born with a disability. Someone might acquire a disability or discover a disability in childhood or as an adult. An elder might realize he or she needs some support services.

People learn about the availability of services in a variety of ways. Some people are channeled into the service system through referrals from a provider. In some cases, referral is mandated. For example, federal and Maine Department of Education regulation govern ChildFind, which links children to early intervention and special education services. ChildFind is the identification, location, and evaluation of children with disabilities to determine eligibility to receive services. For early intervention services, each regional site board must have a ChildFind system in place. The regional boards are responsible for annually notifying all primary referral sources of their obligation to refer children identified in need of evaluation and early intervention services. These primary referral sources include hospitals, physicians, parents, day care programs, local educational agencies, public health facilities, other social service agencies, and other health care providers. For special education services, school administrative units must have a ChildFind program in place to identify school-aged children in need of special education. Children entering kindergarten or transferring from other schools must be screened within the first 30 days of school. The responsibility to identify children with disabilities continues throughout the child’s tenure at the school.

People also learn about services in a less formal manner. Some services are advertised, through outreach efforts, resource guides, the phone book, television, department websites, etc. Some people learn about services by word of mouth. Some people enter the service system in crisis or under duress. For example, a child in need of protective custody will enter the child welfare system and a person in crisis might be connected to mental health or substance abuse treatment. In some cases, a person might begin receiving services after entering the criminal justice system.

Each department has different entry points for enrolling a person for services. For many departments, enrollment occurs through a regional state office. For example, enrollment in MaineCare occurs through a regional DHS office and “enrollment” in probation occurs at a regional probation office. In other cases, people can access publicly funded services directly through contracted providers. Most enrollment for mental health services, long-term care and independent living services is done through contracted providers. In addition, children age birth through 2 are enrolled in early intervention services and children age 3 to 5 are enrolled in special education services through the regional site boards and for special education services through schools.

Table 7. Entry Points for Services

| Dept. | Central or Regional State Office | Provider | School Admin. Unit/Regional Site Board |
|--------------|---|--|---|
| BDS | BDS regional office staff enroll children into children services and persons with mental retardation into mental retardation services. Adults with mental illness can also access services through a BDS regional office. | Children can access services through a community children's services agencies. Community mental health agencies make the eligibility determination for adults with mental illness. Substance abuse providers determine eligibility for substance abuse services. | |
| DOC | Youth Development Center, Maine Correctional Center for Adults, probation | | |
| DOE | | | Early intervention and special education |
| DHS/BCFS | Child protective services | | |
| DHS/BFI | Enrollment in MaineCare and other support programs (MaineCare waiver services accessed either through BFI or through assessment by BDS regional office (mental retardation waiver services), Goold Health Systems (elder and adult waivers administered by BEAS), or AlphaOne (self-directed elder and adult waivers administered by BRS) | | |
| DHS/BEAS | | Information and referral from AAA; Assessment for long-term care services from Goold Health Systems | |
| DHS/BOH | Children with Special Needs, enrolled through central office BOH office | | |
| DOL | Vocational rehabilitation services at CareerCenter | Independent Living Services from AlphaOne or Iris Network; Assessment for self-directed personal care services from AlphaOne. | |

Program Eligibility Criteria

Each state program has criteria for determining whether an individual is qualified to receive services from that program. Program eligibility criteria are used to determine who is eligible to receive services. (For individual services, other eligibility criteria might be applied. For example, a person might be eligible to receive mental health services through BDS, but might not be eligible for a specific service unless the eligibility criteria for that service are met.)

The populations served by each state program are defined by the authorizing legislation governing that program. In some cases, the definition and eligibility criteria are set by the federal government and in some cases they are set by the State. TABLE 8 documents some of the different eligibility criteria used by different programs. Age and disability are the primary characteristics used to define target populations, although there is no standard for how those characteristics are applied.

Age

In general, adult programs serve people beginning at age 18. Children's programs have more sub-categories, and children's services can extend to age 20 for some programs. A person who has not reached the age of 20 at the start of a school year, and who has not graduated with a regular high school diploma may be eligible for special education. For persons in the correctional system, the Department of Corrections can treat a person between age 18 and 20 as a child or an adult, although most people over age 18 are treated as an adult within the correctional system.

Disability

Some programs define eligibility based on an individual's functional abilities or need for services, some programs define eligibility based on a diagnosis, and some programs combine those approaches. For example, BEAS bases eligibility on an individual's need for nursing services, assistance with the activities of daily living, etc. BRS bases eligibility on whether or not an individual's disability is an impediment to finding a job. For persons with mental illness, BDS applies an operational definition that combines a diagnosis of mental illness or personality disorder with functional need. Special education services are also a combination of a specific diagnosis and a functional need for services. Because the purpose of special education services is to ensure access to a free appropriate public education, a child with a diagnosed disability is not eligible for special education services unless it is determined that the disability adversely affects educational performance.

Financial Eligibility. As discussed under FUNDING STREAMS, financial eligibility criteria are applied under the MaineCare program. For children with special needs receiving services through the Bureau of Health, financial eligibility criteria also apply. Otherwise, financial criteria are used to determine the level of cost-sharing, but not eligibility for services. There are no financial eligibility criteria or cost-sharing applied for special education services or vocational rehabilitation services for transition age children.

Table 8. Program Eligibility Criteria by Adult Program

| Department | Age | Disability³¹ |
|---|-------------------|--|
| BDS | | |
| <i>Mental Health Services</i> | 18+ | Serious mental illness (mental illness or a personality disorder with serious functional impairment and requiring hospitalization or emergency services within specified time period). Priority goes to AMHI consent decree class members, people who are homeless, deaf, have addiction disorders, are elderly, or are of minority cultures. |
| <i>Mental Retardation Services</i> | 18+ ³² | Mental retardation or autism. Mental retardation is defined as a condition of significantly sub-average intellectual functioning manifested during a person's developmental period, existing concurrently with demonstrated deficits in adaptive behavior. The developmental period extends from birth to 18 years of age. Mental retardation must have its onset prior to age 18, and impaired adaptive behavior may be reflected in maturational rate, learning ability or social adjustment. Sub-average intellectual functioning is determined by the intelligence quotient obtained by assessment by a general intelligence test (approximately 70, depending on test). ³³ |
| <i>Substance Abuse Services</i> | All ages | Dependent on or abuse alcohol or other substances in violation of the law. ³⁴ |
| DOC | | |
| <i>Correctional facility or probation</i> | 18+ | NA. Adults placed into custody of the Department of Corrections by a court. (Also, under 18 if tried as an adult.) A person might be sentenced to incarceration; probation; or to a split sentence which involves incarceration followed by probation. |

³¹ The criteria used in the table summarize criteria applied in determining eligibility. Statutory definitions of target populations may be different.

³² BDS does include some people in the adult system beginning at age 16.

³³ BDS Rule, 14-197 CMR Chapter 3.

³⁴ 5 M.R.S.A. § 20008(3).

| | | |
|--|----------|--|
| DHS | | |
| <i>Long-Term Care Services for Elders and Adults with Disability</i> | 18+ | Functional eligibility based on need for nursing services, assistance with activities of daily living, or assistance with instrumental activities of daily living. ³⁵ |
| Labor | | |
| <i>Self-Directed Personal Care Services</i> | 18+ | Functional eligibility based on need for nursing services, assistance with activities of daily living, or assistance with instrumental activities of daily living. ³⁶ |
| <i>Vocational Rehabilitation</i> | All ages | Physical or mental impairment which constitutes or results in a substantial impediment to employment. ³⁷ Individual requires vocational rehabilitation services to prepare for, secure, retain, or regain employment. SSI recipients and SSDI beneficiaries are presumed significantly disabled for the purposes of eligibility. |
| <i>Vocational Rehabilitation/Blind</i> | All ages | Significant visual impairment which results in a substantial impediment to employment. ³⁸ |
| <i>Independent Living</i> | All ages | Significant physical or mental disability which results in severe limitation in ability to function independently in family or community setting. ³⁹ |
| <i>Independent Living/Blind</i> | All ages | Less than 20/70 in better eye with best correction or less than 20 degree fields or a significant functional impairment directly related to visual impairments. ⁴⁰ |
| <i>Telecommunications/Deaf</i> | All ages | Profoundly deaf or speech impaired to the extent cannot use telephone for expressive or receptive communication. ⁴¹ |

³⁵ See e.g., DHS Rules, 10-144 CMR Chapter 101, Chapter II, Sections 12, 18 & 19; DHS Rule, 10-149 CMR Chapter 5, Section 63.

³⁶ See e.g., DHS Rule, 10-144 CMR Chapter 101, Chapter II, Sections 22.

³⁷ DOL Rule, 12-152 CMR Chapter 1, Section 4.2

³⁸ DOL Rule, 12-150 CMR Chapter 101.

³⁹ DOL Rule, 12-152 CMR Chapter 7.

⁴⁰ DOL Rule, 12-150 CMR Chapter 105.

⁴¹ DOL Rule, 12-152 CMR Chapter 12.

Table 9. Program Eligibility Criteria by Children's Program

| Agency/Dept. | Age | Disability⁴² |
|---------------------------------|------------|--|
| BDS | | |
| <i>Children's Services</i> | 0 to 5 | Pervasive developmental disorders characterized by severe and pervasive impairment in several areas of development (reciprocal social interaction skills, communications skills, or the presence of stereotyped behavior, interest, and activities). |
| | 6 to 20 | Mental retardation or autism. Mental retardation is defined as a condition of significantly sub-average intellectual functioning manifested during a person's developmental period, existing concurrently with demonstrated deficits in adaptive behavior. The developmental period extends from birth to 18 years of age. Mental retardation must have its onset prior to age 18, and impaired adaptive behavior may be reflected in maturational rate, learning ability or social adjustment. Sub-average intellectual functioning is determined by the intelligence quotient obtained by assessment by a general intelligence test (approximately 70, depending on test). ⁴³ |
| | 0 to 20 | Emotional disturbance, behavioral disorder, or mental illness; assessed as at risk of mental impairment, emotional or behavioral disorder due to established environmental or biological risks using screening instruments adopted by the BDS; or functional impairment assessed in two or more of the following areas: developmentally appropriate self-care; ability to build or maintain satisfactory relationships with peers and adults; self-direction, including behavioral control; capacity to live in a family or family equivalent; inability to learn that is not due to intellectual, sensory, or health factors. |
| <i>Substance Abuse Services</i> | All ages | Dependent on or abuse alcohol or other substances in violation of the law. ⁴⁴ |
| DOC | | |
| <i>Correctional facility</i> | 0 to 21 | NA. Youth placed into the custody of the Department of Corrections by a court. |

⁴² The criteria used in the table summarize criteria applied in determining eligibility. Statutory definitions of target populations may be different.

⁴³ BDS Rule, 14-197 CMR Chapter 3.

⁴⁴ 5 M.R.S.A. § 20008(3).

| DOC (cont'd) | | |
|--|---------|--|
| <i>Probation</i> | 0 to 21 | <p>NA.</p> <ul style="list-style-type: none"> • Charged with crime and agree to probation instead of going to court (first-time offenders); • Put on probation by court; or • Completion of court sentence after release from facility. |
| DHS | | |
| BCFS | 0 to 18 | <p>None.</p> <p>Abused and neglected children; children in circumstances that present a risk of abuse and neglect.⁴⁵</p> |
| BOH | 0 to 18 | <p>One of the following conditions: blood disorders, cardiac defect, childhood oncology, craniofacial anomalies, gastrointestinal disorders, metabolic disorders, ophthalmologic diseases/disorders, orthopedic conditions, neurological conditions, neurosensory conditions, neuromuscular conditions, respiratory conditions</p> <p>Condition restricts physical functioning or causes developmental delays, requires level of care beyond routine and basic care, requires extended pediatric subspecialty treatment or developmental therapeutic services, can be improved or maintained with treatment or services⁴⁶</p> |
| DOE | | |
| <i>At Risk & Identified Disability</i> | 0 to 2 | <p>Developmental delays in cognitive development, physical development, including vision and hearing, communication development, social or emotional development, or adaptive development; or has high probability of resulting in developmental delay.⁴⁷</p> |
| <i>Early Intervention</i> | 3 to 5 | <p>Significant developmental delay, mental retardation, a hearing impairment, deafness, a speech or language impairment, a visual impairment, a behavior impairment, an orthopedic impairment, another health impairment, a learning disability, deaf-blindness, multiple disabilities, autism or a traumatic brain injury.⁴⁸</p> |

⁴⁵ 22 M.R.S.A. § 4003.

⁴⁶ DHS Rule, 10-144 CMR Chapter 272.

⁴⁷ Governed by DOE Rule, 05-071 CMR Chapter 180.

⁴⁸ Governed by DOE Rule, 05-071 CMR Chapter 180.

| DOE (cont'd) | | |
|---|---------|---|
| <i>School Age Special Education</i> | 5 to 20 | Autism, blindness, deafness, an emotional disability, a hearing impairment, mental retardation, multiple disabilities, an orthopedic impairment, another health impairment, a specific learning disability, a speech and language impairment, a traumatic brain injury, and visual impairment including blindness. ⁴⁹ Disability adversely affects educational performance. |
| Labor | | |
| <i>Blind & Visually Impaired Children</i> | 0 to 21 | Visual functioning, with best correction, substantially interferes with education. |

Assessment Process and Tools

The “assessment process” is the process through which an individual’s eligibility for services is determined. For those programs with eligibility predicated on the existence of a disability, the assessment process assesses the existence of a disability and the extent of disability.

Assessment Tools

Some programs have developed or adopted uniform assessment tools to identify an individual’s eligibility for services and level of services. These tools all assess the existence of a disability and the level of disability.

BDS uses the following assessment tools:

Level of Care Utilization System (LOCUS). A standardized assessment instrument for determining the appropriate level of care for adults with mental illness. LOCUS assesses level of need across six domains (danger or risk of harm to self and others; functional status; co-existing medical, addictive and psychiatric conditions; recovery environment; past treatment and recovery history; treatment acceptance and engagement).

Child and Adolescent Level of Care Utilization System (CALOCUS). Tool used to assess children and adults for mental health and substance abuse issues, across six domains (dangerousness or risk of harm to self and others; functional status; co-existing medical, addictive, and psychiatric conditions; recovery environment; past treatment and recovery history; and treatment acceptance and engagement).

Child and Adolescent Functional Assessment Scale (CAFAS). For children and adolescents, measures level of psychosocial functioning across five domains.

The Department of Corrections uses the Youthful Offender Level of Service Inventory and the Juvenile Automated Substance Abuse Evaluation to assess the needs of adolescents on probation and the Adult Living Service Inventory – Revised for persons in the adult correctional system.

⁴⁹ Governed by DOE Rule, 05-071 CMR Chapter 101.

DHS uses the Medical Eligibility Determination (MED) assessment tool to determine eligibility for elders and adults with disabilities. DOL uses the MED to determine eligibility for the self-directed personal care services for adults with physical disabilities. The MED collects demographic, clinical, caregiver, and environmental information. This information is then used to determine eligibility for services. The Bureau of Medical Services also uses the MED for assessing the needs of children with disabilities.

The Assessment Process

Many programs also have a standardized assessment process that governs who participates in determining an individual's need for services and the required elements of an assessment. TABLE 10 and TABLE 11 identifies the person(s) who conducts the assessment and the required elements of an assessment for adult and children's programs, respectively.

Table 10. Assessment Requirements for Adult Programs

| Adults | Person(s) Conducting Assessment | Required Elements of Assessment |
|-----------------------------|--|--|
| BDS | | |
| Mental Health Services | Person chosen or agreed to by individual, with individual's participation. | Individual's strengths and weaknesses; individual perception of own needs; family/guardian input, when appropriate and with consent; personal, family, and social history; emotional, psychiatric, and psychological strengths and needs; physical health status and history, including current prescription and over-the-counter medication use; past and current drug and alcohol use; developmental history; possible sources of assistance, including state and federal entitlement programs; physical and environmental barriers to obtaining service; history of physical or sexual abuse; vocational, educational, social, living, leisure/recreation and medical domains; potential need for crisis intervention services; housing and financial needs; status of Individualized Support Plan; signature of persons performing assessment. ⁵⁰ |
| Mental Retardation Services | BDS Regional Office caseworker | Developmental history; medical information (<i>e.g.</i> , physical examination, occupational, physical, or speech therapy assessments); education information; recent psychological information that includes adaptive behavior assessment and IQ score. |
| Addiction Disorder Services | Licensed professional serving as intake worker ⁵¹ | History of use of alcohol or drugs; treatment history for mental health and substance abuse; pertinent medical information; physical, emotional, educational, etc., needs; medical examination if necessary; emotional or behavioral assessment; family history; vocational history; legal history; social assessment; reports from referral sources. |
| DOC | | |
| Correctional Facility | Caseworker and appropriate licensed professional | Medical, educational, mental health, and substance abuse needs |
| Probation | Probation Officer | Terms of probation determined by court. The Living Service Inventory – Revised (LSIR) used to determine level or risk and service needs. |

⁵⁰ BDS Rule, 14-193 CMR Chapter 6.

⁵¹ *E.g.*, licensed drug and alcohol counselor, licensed clinical professional counselor, licensed social worker.

| | | |
|--|--|--|
| DHS | | |
| Elders & Adults with Disability (agency-based) | Assessing Services Agency (Goold Health Systems) | Medical Eligibility Determination form: physical vital signs, weight, comprehensive systems review, nutritional status, medication review and compliance, health advice, environmental and social needs. ⁵² |
| Protective Services | BEAS caseworker | Determine capacity, dependency, danger or substantial risk of danger, including ability to give informed consent; identify services needs, need for further assessments. |
| Labor | | |
| Personal Care Services/Adults with Physical Disability (self-directed) | Assessing Services Agency (AlphaOne) | Medical Eligibility Determination form: physical vital signs, weight, comprehensive systems review, nutritional status, medication review and compliance, health advice, environmental and social needs. |
| Vocational Rehabilitation | BRS counselor responsible for facilitating; coordinating necessary evaluations | Functional capacity; barriers to and limitations to competitive employment. ⁵³ |
| Independent Living | AlphaOne and the Iris Network | Must be of sufficient scope to determine which services will best meet the current and future needs of individual for functioning more independently in family or community setting. ⁵⁴ |

⁵² DHS Rule, 10-147 CMR Chapter 5, Section 63.

⁵³ DOL Rule, 12-152 CMR Chapter 1, Section 4.2.

⁵⁴ DOL Rule, 12-152 CMR Chapter 7.

Table 11. Assessment Requirements for Children's Programs

| Children | Person(s) Conducting Assessment | Required Elements of Assessment |
|--|---|---|
| BDS | | |
| Mental Health Services | Community agency providing targeted case management services | CAFAS: for children with mental health disorders (school work, community, substance abuse, self-harmful behaviors, etc. FES: identifying family strengths |
| Mental Retardation/ Developmental Delay Services | Community agency providing targeted case management services | CALOCUS: for children with mental retardation or developmental delay (risk of harm, functional status, co-existing disorders, etc. |
| DOC | | |
| Correctional Facility | Assessment unit/multi-disciplinary team | All residents receive the following assessments: developmental family history; substance abuse; educational; psychological; risk/needs; medical. Other assessments, if appropriate, including: sex offender; psychiatric; triennial evaluation for special education. |
| Probation | Juvenile Community Corrections Officer | Personality and behavior; substance abuse history; family role; peers; attitude toward antisocial behavior; connection with school; recreation and leisure activities. |
| Education | | |
| Early Intervention | Early Childhood Team (ECT). ⁵⁵ <ul style="list-style-type: none"> • child's parents; • representative of regional board able to commit resources; • child's teacher or service provider; • administrative case manager; and • prospective providers for the child. Administrative Case Manager responsible for coordinating evaluation and assessment of child. | The assessment must be performed by a person or persons trained to use appropriate assessment methods and procedures. The evaluation and assessment must include a review of the child's current health status and medical history and an evaluation of the child's development. The evaluation of the child's development assesses the child's level of functioning for cognitive development, physical development, communication, social or emotional development, and adaptive development. |

⁵⁵ DOE Rule, 05-071, CMR Chapter 180.

| Education (cont'd) | | |
|---------------------------|--|--|
| Special Education | <p>Pupil Evaluation Team (PET):⁵⁶</p> <ul style="list-style-type: none"> • the student's parents; • regular education teacher; • special education teacher; • school administrative unit representative; • other individuals who have knowledge or special expertise regarding the student; • an individual who can interpret the instructional implications of evaluation results; • whenever appropriate, the student; and • caseworkers from BDS or DOL/BRS. | <p>PET determines what evaluations must be performed, making sure that, when appropriate, the student is assessed in all areas related to the suspected disability, including health, vision, hearing, social and emotional status, behavior, general intelligence, academic performance, communicative status, and motor abilities. The evaluations must be provided by trained personnel. No single evaluation, diagnostic procedure, or source of data shall be used as the sole criterion to determine a student's need for special education. Both measured evidence (as from testing) and evidence based on classroom observations and classroom-based performance shall be used in making this determination.</p> <p>Valid and reliable evaluative instruments and techniques that yield a description of the student as a learner shall be used.</p> |
| DHS | | |
| Protective Custody | Preventive Health Provider | Age and gender specific screenings for physical and developmental and behavioral conditions, vision and hearing, etc., prescribed by MaineCare rule. ⁵⁷ |
| Special Needs | Physician | Verification that condition restricts physical functioning; requires a level of health care beyond routine and basic care; requires periodic subspecialty treatment or developmental therapeutic services for an extended time period; can be maintained and improved by treatment and services. ⁵⁸ |

⁵⁶ DOE Rule, 05-071, CMR Chapter 101, Section 8.6.

⁵⁷ DHS Rule, 10-144 CMR Chapter 101, Chapter 5, Section 2.

⁵⁸ DHS Rule, 10-144 CMR Chapter 272.

Care Plans

The care plan is the set of services identified to meet an individual's needs. The care plan is often developed as part of the assessment process and is often the product of the assessment process. A person receiving services through multiple programs might have multiple care plans. The nature of a care plan can be different depending on the program. In some cases, the care plan is treated as an enforceable contract and contains only services offered through the program and for which the individual is determined to be eligible. Other care plans are more comprehensive in scope but are not enforceable if the State or the provider fails to provide the services.

There are almost as many names for the care plan as there are assessment processes and programs. TABLE 12 identifies the variety of care plans and the required elements.

Table 12. Care Plan Requirements by Program for Adults

| BDS | |
|---|---|
| <i>Individualized Support Plan (ISP) (Persons with Mental Illness)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| <p>Inter-disciplinary team including:</p> <ul style="list-style-type: none"> • individual; • hospital staff if in facility; and • others authorized by individual. | <ul style="list-style-type: none"> • problem statement; • short- and long-range goals; • measurable objectives; • multidisciplinary input and specification of treatment responsibilities; • client input and signature; • signatures of all persons participating in developing the plan; • methods and frequency of treatment, rehabilitation, support; • description of any physical disability and needed accommodation; • criteria for discharge, if applicable; and • unmet needs.⁵⁹ |
| <i>Person Centered Plan (PCP) (Persons with Mental Retardation)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| <ul style="list-style-type: none"> • Individual plan coordinator/facilitator; • Individual support coordinator; • Recipient (unless medically contra-indicated); • Parent/guardian; • Advocate and/or recipient's friend; • Operator or direct service staff of the recipient's home; • Program staff from the recipient's day program or supported employment program; • Any professionals involved or likely to be involved with the recipient's individual plan. <p>The planning team composition shall be determined by each recipient or guardian.</p> | <p>Composition of Person Centered Plan is determined by the individual for whom the plan is made.</p> <p>For Waiver recipients, individual plan is required to outline:</p> <ul style="list-style-type: none"> • the medical and other supportive services to be provided; • the frequency of provision of the services; and • the type of providers authorized/eligible to furnish the services. <p>Planning will occur in a manner that is respectful and reflective of the recipient's preference.⁶⁰</p> |

⁵⁹ BDS Rule, 14-193 CMR Chapter 6.

⁶⁰ DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 21.

| <i>Individual Treatment Plan (ITP) (Persons with Addiction Disorders)</i> | |
|---|---|
| <i>Who Develops</i> | <i>Required Elements</i> |
| Developed by professional or other qualified staff ⁶¹ with consumer. | <ul style="list-style-type: none"> • problems to be addressed during treatment • measurable long-term treatment goals that relate to the problem identified • measurable short-term goals leading to completion of long-term goals, including time frames, measures of success, and treatment procedures to assist in achieving the goals • documentation of the consumer's participation in the planning process |
| DOC | |
| <i>Individual Case Plan (Adults in Correctional Facilities)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Unit Management Team | <ul style="list-style-type: none"> • identification of problem areas identified during intake process • summary of program objectives designed to strengthen demonstrated areas of need • periodic reviews of ICP to evaluate progress and suggest changes or continuation of relevant programs⁶² |
| <i>Case Plan (Adults on Probation)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Probation Officer | None |
| DHS | |
| <i>Plan of Care (Elders/Adults with Physical Disabilities)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Assessing Services Agency (Goold Health Systems or AlphaOne), with input from consumer and others | All services to be delivered to a recipient, including number of hours. Based on assessment outcome scores (Medical Eligibility Determination). Must reflect needs identified through assessment, giving consideration to living arrangement, informal supports and services provided through other sources. ⁶³ |

⁶¹ E.g., registered alcohol and drug counselor, licensed drug and alcohol counselor, licensed clinical professional counselor, licensed social worker.

⁶² DOC Rule, 03-201 CMR Chapter 23, Section 4.

⁶³ See e.g., DHS Rules, 10-144 CMR Chapter 101, Chapter II, Sections 12, 18 & 19; DHS Rule, 10-149 CMR Chapter 5, Section 63.

| <i>Case Plan (Elders/Adults in Protective Custody)</i> | |
|--|---|
| <i>Who Develops</i> | <i>Required Elements</i> |
| BEAS caseworker, with client, consistent with client's circumstances | Realistic objectives stated in terms of measurable outcomes. ⁶⁴ |
| Department of Labor/BRS | |
| <i>Individualized Plan for Employment (IPE)</i>⁶⁵ | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Individual and BRS counselor | <ul style="list-style-type: none"> • specific vocational goal • specific services, with dates & duration • timelines for achieving outcome • provider • terms and conditions • informed of rights • extended services, if applicable |
| <i>Individualized Written Rehabilitation Program (IWRP) Blind & Visually Impaired</i>⁶⁶ | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Individual, and as appropriate, parent, family member, guardian, advocate, or authorized representative, BRS counselor | <ul style="list-style-type: none"> • employment objective • statement of goals and intermediate objectives • specific services, with dates & duration • terms and conditions • individual informed of rights • to be coordinated with IEP if applicable |
| <i>Independent Living Services Plan (SP)</i>⁶⁷ | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| AlphaOne, with participation of person receiving services, and authorized representative if appropriate | <ul style="list-style-type: none"> • independent living goals established by individual • specific services to be provided in order to achieve established goals • individual informed of rights |

⁶⁴ DHS Rule, 10-149 Chapter 5, Section 11.

⁶⁵ DOL Rule, 12-152 CMR Chapter 1.

⁶⁶ DOL Rule, 12-150 CMR Chapter 101

⁶⁷ DOL Rule, 12-152 CMR Chapter 7.

Table 13. Care Plan Requirements by Program for Children

| BDS | |
|---|---|
| <i>Individual Service Plan (ISP)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Mental health provider; parent/guardian; and child if 14 or older | <ul style="list-style-type: none"> • statement of specific strengths and treatment or service needs • short-term and long-term goals • statement of the rationale for particular treatment • specification of treatment responsibility and involvement of child, staff, family, etc. to attain goals • assessment of whether child can be safely discharged • documentation of current discharge planning |
| DOC | |
| <i>Individual Intervention Plan (Youth in Correctional Facilities)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Assessment unit/multi-disciplinary team, and Juvenile Community Corrections Officer | <p>Services and activities in response to identified needs, including:</p> <ul style="list-style-type: none"> • substance abuse treatment; • education plan; • behavioral services; • mental health treatment; • cognitive skill program; • recreational activities; and • family relationships. |
| <i>Case Plan (Youth on Probation)</i> | |
| <i>Who Develops</i> | <i>Required Elements</i> |
| Juvenile Community Corrections Officer | Treatments in response to risk factors identified in assessment process. |

Education

Individualized Education Plan (IEP) (Special Education Services)⁶⁸

| <i>Who Develops</i> | <i>Required Elements</i> |
|-----------------------------|--|
| Pupil Evaluation Team (PET) | <ul style="list-style-type: none">• the student's present level of educational performance;• measurable annual goals;• special education and supportive services and supplemental aids to be provided to the student;• transition services for a child beginning at age 14 and older;• an explanation of the extent, if any, that the child will not participate with students who do not have disabilities;• a statement that the student has been informed of his or her special education rights under state and federal law, at least one year before the child turns 18; and• a statement of considerations in developing the IEP which include but are not limited to: strategies, including the positive behavioral interventions, strategies, and supports to address behavior, the communication needs of the student; and whether the student requires assistive technology and devices and services. <p>The IEP must be reviewed and revised at least annually.</p> |

⁶⁸ DOE Rule, 05-071, CMR Chapter 101.

Individualized Family Services Plan (IFSP) (Early Intervention Services)⁶⁹

| <i>Who Develops</i> | <i>Required Elements</i> |
|---------------------|---|
| | <ul style="list-style-type: none"> • the child's present functioning; • goals and objectives; • special education and related services to be provided; • projected initiation of services and location, frequency, intensity and anticipated duration of services, including whether services are provided on an individual or group basis; • a statement of any individual modifications in the administration of state- or district-wide assessments; • a statement of any transition services; • a statement about the family's resources, priorities, and concerns related to enhancing the development of the child and the role of the family in implementing the IFSP/IEP; and • medical and social service needs and how they will be obtained. <p>The IFSP must be reviewed every six months for a child birth to two, at least yearly for a child three to five, or more frequently if the family requests it or a review is otherwise warranted.</p> |

DHS

Plan of Care (BCFS)

| <i>Who Develops</i> | <i>Required Elements</i> |
|------------------------------------|---|
| Preventive Health Program provider | Any medically necessary health care, diagnostic service, treatment or other measure documented by the screening to correct or ameliorate defects, physical illness or mental illnesses. |

Plan of Care (BOH)

| <i>Who Develops</i> | <i>Required Elements</i> |
|---------------------|---|
| Sub-specialist | A medical or therapeutic treatment evaluation and report that clearly define the recommendations for subspecialty intervention (used to obtain prior authorization for services). |

⁶⁹ DOE Rule, 05-071, CMR Chapter 180.

Settings

The key issue under the *Olmstead* decision is whether a state is providing services to persons with disabilities in the most integrated setting appropriate to their needs. While *Olmstead* focused on “institutions,” here we do not limit ourselves to only institutional settings. In this section, we examine the range of settings in which a person might reside while receiving services from the State and the systems Maine has in place to ensure that each person is served in the most integrated setting appropriate to that individual’s needs and preferences.

The setting in which a person resides is one measure of the degree to which that person is integrated within a community. Different settings are considered more or less integrated depending on how one measures “integration.” Some people think that a setting is not “integrated” if only persons with disabilities inhabit that setting. Others think that a residential setting for only persons with disabilities might be “integrated” if it is a choice that provides greater independence or opportunity. For the purposes of this document, we define the degree of integration as a function of the degree of control a person has over space and activities. For example, under this definition, institutional settings are considered to be the most restrictive settings because residents of institutional settings (*e.g.*, a nursing facility or psychiatric facility) have less choice and the least control over their privacy, when they eat, what time they get up in the morning, who they associate with, how they use their time, etc. The least restrictive settings are those where a person has maximum choice and the most control over personal space and use of time.

Range of Settings

A person with a disability might reside in any of a number of different settings. For the purposes of this document, the range of settings are grouped as follows:

Institutional settings. Institutional settings include nursing facilities, rehabilitation hospitals, psychiatric units in hospitals and psychiatric hospitals, and intermediate care facilities for persons with mental retardation.

Other licensed residential settings. Residential facilities include facilities and homes licensed by the State, including residential care facilities (also known as boarding facilities and adult foster homes), residential child care facilities, adult family care homes, specialized children’s foster home, congregate housing, and residential treatment facilities. Residential treatment facilities are residential care or child care facilities with licensed treatment programs. We do not attempt to characterize all of these settings as “more integrated” than all of the institutional settings. Some people see some of these other licensed residential settings as institutional settings or as segregated.

Unlicensed residences or settings. This category includes a wide range of settings, including a private residence (a person’s own home, family home, apartment, private boarding homes, shared home or apartment), boarding house and other settings not requiring the State’s involvement in licensing or providing food and lodging. Unlicensed shelters, the street, and other settings where the homeless live, are included here.

Correctional facilities. The Department of Corrections operates six adult prisons and two youth facilities.

Each of these groups of settings is described in more detail over the next four sections. We also discuss separately persons receiving out-of-state services funded through Maine programs.

Types of Institutional Settings

Maine has three types of institutional settings that are or can become long term residential settings for persons with disabilities:

- intermediate care facilities for persons with mental retardation;
- nursing facilities; and
- psychiatric facilities or units.

TABLE 14 identifies the population groups served in these three institutions.

Table 14. Institutional Setting by Population Group Served

| Setting | Persons Served by Type of Disability | | | | | |
|-------------------------------|--------------------------------------|-------|--------------------|-------|---|-------|
| | Physical Disability | | Mental Retardation | | Mental Illness/ Emotional Disability | |
| | Adult | Child | Adult | Child | Adult | Child |
| ICF-MR | | | ✓ | ✓ | | |
| Nursing Facility | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Psychiatric Facility/ Unit | | | | | ✓ | ✓ |

The next four sections describe each of these institutional settings, the systems for minimizing the State's reliance on these institutions, and the services available to support transition out of an institution. The fifth section reviews some of the available data about the people residing in these institutional settings.

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR). There are two types of intermediate care facilities for persons with mental retardation (ICF-MR), each providing different levels of care:

- *Nursing.* A nursing facility ICF-MR serves the needs of persons who require at least eight hours per day of licensed nurse supervision of coordinated health treatment, rehabilitation and habilitation and active treatment services.
- *Group.* A group home facility ICF-MR provides a protective setting for 24-hour non-nursing supervision of persons for the purpose of assuring the coordination of habilitation, health, rehabilitation and active treatment services.

Both types of ICF-MR have at least four residents. ICFs-MR are licensed by the Bureau of Medical Services.⁷⁰

The State operates three ICFs-MR:

- the Elizabeth Levinson Center in Bangor, a nursing ICF-MR for children and adolescents up to age twenty-one;
- Aroostook Residential Center in Presque Isle, a group ICF-MR serving adults; and
- Freeport Towne Square, a group ICF-MR serving adults.

In addition, Maine has 13 licensed group ICFs-MR and 13 licensed nursing ICFs-MR. The number of licensed beds for Maine's ICFs-MR is summarized:

| ICF-MR | Licensed Beds |
|----------------------------------|---------------|
| Elizabeth Levinson Center | 20 |
| Aroostook Residential Center | 6 |
| Freeport Towne Square | 6 |
| Private Nursing ICFs-MR (n = 13) | 13 (ave.) |
| Private Group ICFs-MR (n = 13) | 6 (ave.) |

According to licensing regulations, ICFs-MR are intended to be home-like. ICFs-MR are to be small enough to ensure the development of meaningful interpersonal relationships among clients and between clients and staff; and must contain at least a bedroom, living room, bathroom, recreation room, connecting areas, dining room, and kitchen.⁷¹

Admissions. A person may be admitted to an ICF-MR if his or her needs can be met at the facility and an interdisciplinary team has determined that admission is the least restrictive and best available plan for that person. In some cases, a person might be admitted to an ICF-MR when it is not the best plan. In those cases the inter-disciplinary team must actively explore alternative settings.

Reassessment and Ongoing Monitoring. Every six months the Bureau of Medical Services reviews the quality, quantity and continued medical necessity of services for persons receiving services under the MaineCare program.

Discharge Planning and Transition. The ICF-MR is responsible for transferring the information necessary to achieve optimal continuity of care. For persons moving to their own home, the ICF-MR is to provide information about community resources.

Nursing Facilities. Nursing facilities serve persons with a need for professional nursing or rehabilitative services on a daily basis. In addition to nursing services, nursing facilities provide assistance with the activities of daily living, and other services. Nursing facilities also provide short term rehabilitation services for persons recovering from an injury or illness.

⁷⁰ Pursuant to DHS Rule, 10-144 CMR Chapter 118.

⁷¹ DHS Rule, 10-144 CMR Chapter 118.

There are 126 nursing facilities in Maine. The total number of licensed beds is 7900, and 4900 persons funded through MaineCare were residing in nursing facilities as of December, 2001.⁷²

Admission. By statute, all persons seeking admission to a nursing facility must be assessed to determine whether nursing facility services are appropriate to meet their needs, whether or not those services are paid for by public or private sources.⁷³ DHS is also required to determine whether a home or other community-based setting is clinically appropriate and cost-effective. When home-based services are determined to be appropriate and cost-effective, DHS is obligated by law to tell the consumer about this option, develop a proposed community care plan, and offer the community care plan and case management services to the consumer on a sliding scale basis. Through this process, nursing facility services are reserved for only people for whom it is clinically appropriate and who choose it.

Reassessment and Ongoing Monitoring. Nursing facilities are required to monitor the continued need of residents for nursing facility level of care and request the Assessing Service Agency conduct an assessment when it appears the nursing facility services are no longer required. Nursing facility residents are also automatically reassessed once a year to determine continued eligibility for nursing facility services and a continued choice to live in a nursing facility.

Discharge Planning and Transition. The nursing facility is responsible for transferring the information necessary to achieve optimal continuity of care. For persons moving to their own home, the nursing facility is to provide information about community resources.

Psychiatric Facilities and Units. People with serious mental illness in need of inpatient services can be served as patients at a psychiatric facility or at a psychiatric unit within a general hospital. The Bureau of Medical Services, within DHS, licenses staffing, procedures, etc., for psychiatric hospitals and units.⁷⁴

Maine, through the Department of Behavioral and Developmental Services (BDS), operates two psychiatric facilities, the Augusta Mental Health Institute (AMHI) and the Bangor Mental Health Institute (BMHI). AMHI is subject to a consent decree which requires BDS to comply with a judicially enforced settlement agreement. In addition, there are two private licensed psychiatric facilities, Acadia Hospital in Bangor and Spring Harbor in South Portland.

⁷² Nursing facilities are licensed by the Bureau of Medical Services pursuant to DHS Rule, 10-144 CMR Chapter 110.

⁷³ 22 M.R.S.A. § 3174-I. This assessment is conducted by Goold Health Systems. See ASSESSMENT PROCESS AND TOOLS.

⁷⁴ DHS Rule, 10-144 CMR Chapter 112.

Maine’s psychiatric hospitals, which provide short term, acute care, have the following licensed beds:

| Psychiatric Hospital | Licensed Beds |
|---------------------------------|----------------------|
| Augusta Mental Health Institute | 103 |
| Bangor Mental Health Institute | 100 |
| Spring Harbor, South Portland | 111 ⁷⁵ |
| Acadia Hospital, Bangor | 100 ⁷⁶ |

Maine also has eight general hospitals that operate psychiatric inpatient units, including Aroostook Medical Center, Northern Maine Medical Center, PenBay Medical Center, Southern Maine Medical Center, Maine Medical Center, MaineGeneral, Mid-Coast Hospital, and St. Mary’s Medical Center.⁷⁷ Six of these eight hospitals provide emergency, involuntary psychiatric admissions.

Admission. Admission to a psychiatric facility or unit can be voluntary or involuntary. BDS rule requires crisis and emergency service providers to consider all other options before admission to a psychiatric facility.⁷⁸ Providers are to refer persons on to appropriate services when required, available and desired. MaineCare rule requires that an inpatient hospital stay in a psychiatric facility be permitted only if a person with a psychiatric diagnosis has needs that cannot be met in a less restrictive setting.⁷⁹ A person may also be involuntarily admitted to a psychiatric hospital if it is believed that the person is mentally ill and poses a likelihood of serious harm to self or others. Involuntary admissions must be reviewed and approved by a judge.⁸⁰

Reassessment and Ongoing Monitoring. A treatment plan must be written within three days of admission and must include criteria for discharge or release to a less restrictive setting. Long term psychiatric services in a psychiatric rehabilitation unit are limited to those persons with a diagnosis of a severe mental illness; a continuing disability resulting from the mental disorder that interferes with life activities and a current spell of psychiatric illness exceeding six months.⁸¹ To be reimbursed by MaineCare, inpatient stays extending past 120 must receive prior authorization. The treatment plan is reviewed every 30 days.

Discharge Planning & Transition. BDS licensing rules require that treatment and discharge planning be developed in coordination with the Individualized Support Plan and that the psychiatric facility document individual preference for living situation. An individual can also request that a community support worker assist in discharge planning.

⁷⁵ 6 beds licensed for involuntary admissions.

⁷⁶ 16 beds licensed for involuntary admissions.

⁷⁷ These psychiatric units are treated as general hospitals for the purpose of licensing and reimbursement.

⁷⁸ BDS Rule, 14-193 CMR Chapter 6.

⁷⁹ DHS Rule, 10-144 CMR, Chapter 101, Chapter II, Section 46.

⁸⁰ 34-B M.R.S.A. § 3864.

⁸¹ DHS Rule, 10-144 CMR Chapter 112.

People Residing in Institutional Settings

Table 15. Number of MaineCare Members Spending Any Time in Institutional Setting by Age, Fiscal Year 2001

| Age | ICF-MR | Nursing Facility | Psychiatric Unit/Facility⁸² |
|--------------|---------------|-------------------------|---|
| 0-20 | 18 | 51 | 977 |
| 21-59 | 223 | 665 | 1,717 |
| 60-64 | 16 | 296 | 46 |
| 65+ | 33 | 7,941 | 78 |

Other Licensed Residential Settings

A variety of other licensed residential settings serve a variety of needs. This section reviews the different types of other licensed residential settings, including:

- adult family care homes;
- assisted housing (including congregate housing);
- residential care (and treatment) facilities;
- residential child care (and treatment) facilities;
- specialized children's foster home;
- emergency shelters for children;
- residential schools; and
- shelters for homeless children.

Each of these settings serves different population groups, as identified in TABLE 16.

⁸² Includes private and state-operated psychiatric hospitals; excludes stays in psychiatric units within general hospitals.

Table 16. Other Licensed Residential Setting by Population Group Served

| Setting | Persons Served by Type of Disability | | | | | | | |
|---|--------------------------------------|-------|---|-------|-----------------------|-------|-----------------------|-------|
| | Physical Disability | | Mental Illness/ Dementia/ Emotional Disability | | Mental Retardation | | Addiction Disorder | |
| | Adult | Child | Adult | Child | Adult | Child | Adult | Child |
| Adult Family Care Home | ✓ | | ✓ | | | | | |
| Congregate Housing | ✓ | | ✓ | | ✓ | | | |
| Residential Care/ Treatment Facility | ✓ | | ✓ | | ✓ | | ✓ | |
| Residential Child Care/ Treatment Facility | | ✓ | | ✓ | | ✓ | | ✓ |
| Specialized Children's Foster Home | | ✓ | | ✓ | | ✓ | | ✓ |
| Emergency Shelters for Children | | ✓ | | ✓ | | ✓ | | ✓ |
| Shelters for Homeless Children | | ✓ | | ✓ | | ✓ | | ✓ |

Adult Family Care Home (AFCH). An Adult Family Care Home (AFCH) is a residential-style setting in which personal care and other services are provided to six or fewer residents.⁸³ The average number of licensed beds is 5.

Congregate Housing. Congregate housing is residential housing consisting of private dwelling units with an individual bathroom and an individual food preparation area, in addition to central dining facilities, and within which a congregate housing supportive services program serves occupants.⁸⁴ There are four levels of licensure reflecting the level of services offered. A congregate housing facility with a Type IV license is authorized to provide nursing services, personal assistance services, and medication administration.

⁸³ The AFCH is licensed by the Bureau of Medical Services pursuant to DHS Rule, 10-144 CMR Chapter 121.

⁸⁴ Congregate Housing is licensed by the BEAS pursuant to DHS Rule, 10-144 CMR Chapter 113.

The total number of licensed beds is 8200, with 3500 persons residing in congregate housing receiving public funding each year.

Residential Child Care Facility (RCCF). A Residential Child Care Facility (RCCF) is a residence maintained for one or more children by anyone other than a relative which provides board and care on a regular, twenty-four hour a day residential basis. A residential child care facility may administer licensed programs, including an educational program licensed by the Department of Education, or substance abuse or mental health treatment programs licensed by BDS. A residential treatment facility with “secure capacity” provides a mental health intensive treatment program for children whose mental health presents a likely threat of harm to themselves or others and whose treatment requires a secure setting.⁸⁵

Private residential programs predominantly serve children with emotional disabilities. In addition, RCCFs can offer adolescent rehabilitation services for substance abuse treatment (expected 3 to 12 months per admission). Residential child care facilities bedrooms are to have no more than 4 children in a bedroom without prior approval. Other living space is shared by residents.

In 2003, excluding shelters, the total number of licensed beds is 1323.⁸⁶

Residential Care Facilities. The Residential Care Facility (RCF) is the largest category of non-institutional licensed residential facility. This licensing category covers a very wide range of residential facilities.⁸⁷ To begin, there are two levels of RCF: an RCF I has a licensed capacity for six or fewer residents; an RCF II is licensed for seven or more residents.

Residents in a residential care facility might share two to a bedroom, with other living space common to all residents. RCF IIs in Maine range in size from 7 to 144 licensed beds. Over 80% of Maine’s RCF IIs have more than 10 licensed beds, with an average of 27 licensed beds.

Some of the different roles for the residential care or treatment facility include providing:

- medical and remedial services;
- community residences for persons with mental illness;
- community residences for persons with mental retardation;
- medical detoxification for substance abuse (7-day limit on length of stay for each admission);
- residential rehabilitation for substance abuse treatment (30-day limit on length of stay for each admission);
- halfway house services (180-day limit on length of stay for each admission);
- extended care services for substance abuse (270-day limit on length of stay for each admission per year); and
- extended shelter on waiting list for substance abuse treatment (45-day limit).

⁸⁵ The RCCF is licensed by the Community Services Center pursuant to DHS Rule, 10-148 CMR Chapter 18.

⁸⁶ Information obtained from Conrad Thibault, Bureau of Family and Children’s Services, DHS on 2/14/03.

⁸⁷ The Residential Care Facility is licensed by the Bureau of Medical Services pursuant to DHS Rule, 10-144 CMR Chapter 113.

Based on the different roles an RCF may be known by other names. Residential care facilities providing medical and remedial services are also known as adult foster homes (RCF I) or a group home, or boarding, or board and care, facilities (RCF II). Community residences for persons with mental retardation are sometimes called “Medicaid waiver homes.” RCFs providing substance abuse treatment might be know as a halfway house, a shelter, etc.

TABLE 17 identifies the number of MaineCare members spending any time in residential care and residential child care facilities in Fiscal Year 2001.

Table 17. MaineCare Members Spending Any Time in Private Non-Medical Institutions by Type of Institution and Age

| Age | Substance Abuse | Children’s Treatment | Mental Retardation | Mental Illness | Medical & Remedial |
|--------------|-----------------|----------------------|--------------------|----------------|--------------------|
| 0-20 | 80 | 2950 | 7 | 68 | 4 |
| 21-59 | 557 | 29 | 271 | 493 | 253 |
| 60-64 | 13 | 1 | 31 | 26 | 78 |
| 65+ | 4 | 0 | 54 | 45 | 1238 |
| TOTAL | 651 | 2977 | 351 | 621 | 1564 |

Shelters. Maine licenses two types of shelters for children.

- *Emergency Shelter for Children.* Emergency shelters provide 24-hour per day services to children for no more than 30 consecutive days and do not necessarily serve persons with disabilities.⁸⁸
- *Shelter for Homeless Children.* These shelters provide overnight lodging and supervision to children 10 years of age or older for no more than 30 consecutive nights and do not necessarily serve persons with disabilities.⁸⁹

Specialized Children’s Foster Home. Specialized Children’s Foster Homes provide care to no more than two children with a moderate or severe physical, emotional, mental or behavioral condition requiring the involvement of the foster parents in the treatment plan. (The foster home can house up to four children total.) Foster parents are required to have specialized knowledge and training to fulfill their role as substitute parents. Specialized Children’s Foster Homes are also known as therapeutic or treatment level foster homes.⁹⁰

⁸⁸ Emergency Shelters for Children are licensed by the Community Services Center pursuant to DHS Rule, 10-148 CMR Chapter 9.

⁸⁹ A Shelter for Homeless Children is licensed by the Community Services Center pursuant to DHS Rule, 10-148 CMR Chapter 8.

⁹⁰ Specialized Children’s Foster Homes are licensed by the Community Services Center pursuant to DHS Rule, 10-148 CMR Chapter 15.

Unlicensed Settings

People may live in a variety of settings not licensed by the State. These settings include:

- own home;
- family home;
- own apartment;
- shared home or apartment;
- eating and lodging facilities;
- unlicensed shelters; and
- the street.

The services available to persons residing in these settings is described in COMMUNITY- AND HOME-BASED SERVICES.

Correctional Facilities

Correctional facilities do not fit neatly within the framework of other settings discussed here. Correctional facilities receive individuals into custody without regard to whether they have a disability. Second, in addition to providing care and maintenance, correctional settings also serve the role of carrying out sentences of incarceration ordered by courts. Neither the individual nor the department has choice or discretion over whether the individual is taken into custody. Involuntary incarceration in a correctional facility is, however, similar to situations such as involuntary hospitalization, placement in group homes, foster homes, nursing homes or homeless shelters, which do not reflect voluntary selection of an individual's residential setting. In spite of the inherently restrictive environment of a correctional facility, there is a range of integration as defined above, where inmates and juvenile residents have varying degrees of control over their space, activities and interactions with others. Any analysis of integration must consider the degree of integration within the correctional environment as well as the role of the Department of Corrections in relation to other state agencies providing services to individuals with disabilities.

Adult Prisons. The DOC operates six adult institutions of varying levels of security, and of varying size. One facility, the Maine Correctional Center, in Windham, serves as the primary intake facility for the entire correctional system. It is also the prison in which inmates with special needs, including serious medical conditions and disabilities, are placed.

Most adults sentenced to prison go through an intake process at the Maine Correctional Center. The initial process, performed by the intake officer, identifies major medical concerns and other immediate health care and treatment needs. Within 45 days a more comprehensive assessment takes place, as part of the classification process. (The classification process is also used to determine the person's security risk in the prison system.) This assessment is conducted by a case worker assigned to the inmate for the duration of his or her sentence. The case worker assesses whether the person has any medical, educational, mental health, and substance abuse needs and makes a recommendation for treatment if necessary.

In general, services delivered through correctional facilities include:

- medical care;
- mental health treatment;
- substance abuse treatment;
- trades and work programs;
- educational programming;
- public service programs; and
- life skills counseling.

The availability and delivery of services depends on the setting, the age, health and needs of the person and safety and security considerations.

All prisons provide medical services. Depending on the facility, a variety of other services are available. At the Maine Correctional Center, services are more comprehensive given the role of that facility in meeting special needs of inmates. The Maine Correctional Center has a new therapeutic community for substance abuse treatment. A collaborative project with the Office of Substance Abuse within the Department of Behavioral and Developmental Services, this program provides substance abuse treatment to up to 40 people in a wholly separate community. Other prisons also have less intensive substance abuse services. Other prisons also provide mental health services. Prison services are provided by the DOC staff or by providers under contract with the Department of Corrections.

Youth Facilities. The DOC operates two youth facilities, the Long Creek Youth Development Center (South Portland) and the Mountain View Youth Development Center (Charleston), with educational and treatment programs for extended time periods. Upon entry into one of the youth development centers, a needs assessment, called a “clinical” is conducted and a “prescriptive plan” is developed. Each adolescent is assigned to a unit director who is responsible for developing a day-to-day schedule for the person based on the prescriptive plan. The unit director is also responsible for seeing that the plan is implemented. An adolescent’s stay at a youth development center is indefinite, conditioned on completion of the elements in the plan. The youth centers provides a range of medical, mental health, and substance abuse services.

Out-of-State Settings

Some persons with disabilities are served in out-of-state settings.

Schools. Some children are placed in out-of-state educational settings because the necessary expertise is not available in Maine. In 2000, there were 29 students placed out of state through the School Administrative Units. These children include 17 blind/deaf-blind/multiply disabled students placed at Perkins School for the Blind; two students with autism; four students with special learning disabilities; three students with mental retardation; and two students with emotional disability for whom out-of-state placement was closer to home than in-state placement; and one student labeled “other health impaired.” The number of educational out-of-state placements is estimated to be fewer than 20 currently. An out-of-state placement is presumed to be more restrictive than an in-state placement and is therefore subject to heightened scrutiny by DOE. The SAU must request approval from the Division of Special Services,

explaining why in-state placement is not possible, what efforts were made to find an appropriate in-state placement, and why in-state placement efforts were not successful or were not considered appropriate.

Other Out-of-State Placements. In some cases, children with emotional disabilities, brain injury or other disabilities are placed out-of-state for services other than special education services, because those services are not available in-state. In December 2001, the census for children authorized or placed out-of-state by a state agency was 107. These numbers are a significant improvement from January 1999, when 205 children were placed out-of-state.

Home- and Community-Based Services

The State provides a spectrum of services to support living at home or in the community. For the purposes of this document, all of the services offered by the State are grouped into these categories:

- service coordination;
- community residential services;
- in-home and personal supports;
- educational services;
- early intervention services;
- independent living services;
- mental health services;
- other mental retardation services;
- other disability services;
- community substance abuse treatment;
- other children's services; and
- community correctional services.

The next sections describe these four groups of services.

Service Coordination

Many people with disabilities have complex needs requiring multiple services. Compounding the challenge of meeting those needs is the complexity of the service system -- finding out what services are available and how to obtain them can be confusing, overwhelming, even impossible, without the help of someone who knows the system. The service coordinator can play a critical role in linking an individual or family with children with the services necessary for living in the most integrated setting appropriate for that individual or child. (For the purposes of this document, we use "service coordination" to mean primarily the case management services offered as "targeted case management" services under MaineCare, including case management services offered by community support workers,⁹¹ as well as other service coordination offered through other state agencies.)

⁹¹ DHS Rule, 10-144 CMR, Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 13 and 17.

The definition of “service coordination” can vary across programs and within programs, depending on the needs of the population served. In general, service coordination includes:

Conducting intake and assessment. The process of identifying the client's medical, social, educational, and other conditions and needs. (See ASSESSMENT PROCESS AND TOOLS for more discussion of the assessment process.)

Developing the plan of care or service plan: The process of determining what services and resources are necessary to meet the identified needs and how they might be most appropriately delivered. The plan of care is designed to maintain current service delivery and to resolve gaps in services so that comprehensive care is attained. (See CARE PLANS for more discussion of the care of plan.)

Coordination and advocacy: The process of facilitating the client's access to the services and resources identified in the care plan by advocating on behalf of the client for appropriate community resources and coordinating the multiple providers of social and health services defined in the care plan.

Monitoring: The process of ensuring that the client's care plan is implemented and assessing the client's progress toward meeting the objectives outlined in the care plan.

Evaluation: The process of determining whether the care plan is appropriate, whether a new plan is necessary, or whether services should be terminated.

Service coordination is available through different programs and for different types and levels of need. The service coordinator might be a state employee or a provider under contract with a state agency. Depending on the program, the service coordinator can have a different name or a different function and the service coordination function will have a focus specific to the funding agency. For example, service coordination will be different depending on whether or not the person served is a child under the protection of the Bureau of Child and Family Services or a child receiving special education services in a school. Many people will fit within more than one category and will have more than one care manager.

Depending on the population group, there are different levels of service coordination available. For example, for adults with severe and disabling mental illness, three levels of service coordination are available. Community support workers provide case management and supportive services to consumers with light to moderate intensity of need. Intensive case managers are trained to seek out and engage individuals who may not seek out services, and who may be actively resistant to services. ICM services are provided to consumers who are homeless, dually diagnosed with substance abuse, incarcerated or who do not choose to use other case management services but have a high level of need. Assertive community treatment teams are a multi-disciplinary approach to community support services and to case management and provide high intensity contact with consumers who resist engaging in and continuing with services.

MaineCare is the primary funding source for service coordination service, although some service coordination is available through programs not funded by MaineCare (*e.g.*, some children receiving special education receive service coordination even if not funded by MaineCare; BRS employment counselors provide some limited coordination services in the course of providing vocational rehabilitation services). TABLE19 identifies the different groups for whom service coordination is funded through MaineCare and the provider of service coordination for that population group. TABLE 18 identifies the eligibility criteria for service coordination under MaineCare for each population group.⁹²

⁹² Information for TABLES 18 and 19 is taken from DHS Rules, 10-144 CMR, Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 13 and 17.

Table 18. Types of Service Coordinators Funded Through MaineCare Across Population Groups

| Population Group | Service Coordinator |
|---|--|
| Adults with mental retardation | Individual Support Coordinator (employee of BDS regional office) |
| Persons with severe and disabling mental illness | Designated Community Support Providers, under contract with BDS. Intensive case management providers, employees of BDS. Assertive community treatment providers, multidisciplinary teams of providers under contract with BDS. |
| Persons with HIV infection | Case manager approved by Bureau of Child and Family Services (social worker, registered nurse, other qualified staff). |
| Infants and children birth through age five with or at risk for developmental delay | Designated Case Manager, as determined by the early childhood team accessed through a Community Development Services provider or by a Head Start intake team accessed through a local Community Action Program. |
| Families of children who are abused or neglected, or at risk of abuse or neglect | Designated staff of the Bureau of Child and Family Services (BCFS) or private agencies under contract with BCFS. |
| Children and young adults in the care or custody of the State | Designated staff in the regional and central offices of the Bureau of Child and Family Services or any agency holding a contract with the Bureau of Child and Family Services to provide case management services. |
| Adults in need of protective services | Caseworker, employed by the Bureau of Elder and Adult Services, Department of Human Services. |
| Children and adolescents with emotional disturbance, behavioral disorder, mental illness, mental retardation, or pervasive developmental disorder | Agencies under contract to BDS (Some service coordination can be provided by either professional staff or persons who have parented a child with special needs). |
| Juveniles referred or under the supervision of juvenile corrections caseworkers | Juvenile community corrections officer employed by the Department of Corrections |
| Pregnant or postpartum women and those at risk of inadequate parenting | Approved staff of Bureau of Health, Division of Community and Family Health, municipal health departments, community health nursing grantees, and adolescent pregnancy projects funded by DHS. |
| Adults with long-term care needs | State-designated Home Care Coordinating Agency (HCCA). BEAS contracts with Elders Independence of Maine (EIM) for agency-directed services; BRS will contract with AlphaOne for self-directed care services. |
| Persons with psychoactive substance dependence | Designated Case Management Provider, under contract with Department of Behavioral and Developmental Services. |
| Children and adolescents exhibiting high risk behaviors and approved for special education and supportive services | Plan or case manager designated by the Student Assistance Team; staff of either local school administrative unit or approved private school. |

Table 19. Eligibility Criteria for Selected Types of Service Coordination funded by MaineCare

| Population Group | Age Group | Eligibility Requirements |
|---|------------------|---|
| Adults with mental retardation (BDS) | 18+ | The consumer fits the statutory definition of mental retardation of Title 34B M.R.S.A §5001, or fits the statutory definition of autism in Title 34B M.R.S.A. §6002, and cannot reside in an Intermediate Care Facility for Persons with Mental Retardation (ICF/MR) |
| Persons with severe and disabling mental illness (BDS) | 18+ | The consumer has been diagnosed with a major and severe mental illness, or has been diagnosed with a personality disorder or mental retardation combined with: <ul style="list-style-type: none"> • a risk of suicide; • confusion, disorientation, or delusional thinking that impairs ability to function; • active hallucinations; • bizarre behavior with severely disturbed mood; • severe agitation or hyperactivity; • grossly inappropriate or grossly blunted affect; or • inability for self care creating a risk to life, limb, or severe medical consequences. |
| Persons with HIV (DHS) | Any age | The consumer has been diagnosed with HIV or AIDS, or has tested positive for HIV |
| Infants and children through age five at risk for developmental delays (BDS) | Age 5 or younger | <ul style="list-style-type: none"> • An accepted diagnostic procedure has identified a developmental delay in: <ul style="list-style-type: none"> - physical development; - cognitive development; - communication development; - adaptive development; or - behavioral or emotional development; • The infant or child has a diagnosed or documented physical or mental condition that suggests damage to the central nervous system; or • A professional assessment has found certain risk factors for developmental delay. |
| Families of children who are abused or neglected or who are at risk of abuse or neglect | Any age | A parent or child if the child is under age 18 and is abused or neglected, or is suspected to be at risk of abuse or neglect. |

| Population Group | Age Group | Eligibility Requirements |
|---|--|--|
| Children and young adults who are in the care or custody of the State | 0-20 | A child or young adult up to age 21 if the individual is either in the custody of DHS or of an agency in another state pursuant to court order, or is in voluntary care of DHS or an agency in another state pursuant to a written agreement, or a family receiving post-adoption services. |
| Adults in need of protective services (DHS) | Age 18+ or a legally emancipated minor | A person who: <ul style="list-style-type: none"> • cannot make or communicate responsible decisions about their own care and needs because of mental or physical disability or illness, or mental incapacity; or • is completely dependent upon others for emotional and physical care and would be endangered without it. |
| Children and adolescents with emotional disturbance, behavioral disorder, mental illness, mental retardation, or pervasive developmental disorder (BDS) | Age 20 or younger | A person who: <ul style="list-style-type: none"> • has been diagnosed with, or is at-risk of emotional disturbance, behavioral disorder or mental illness; • has been assessed with two or more functional impairments in: <ul style="list-style-type: none"> - developmentally appropriate self-care; - ability to maintain satisfactory relationships with peers and adults; - self-direction and self-control; - ability to live in a family or family equivalent; and - an inability to learn that is not caused by intellectual, sensory, or health problems; • fits the statutory definition of mental retardation or the clinical definition of pervasive developmental disorders; or • is age 5 or younger with a diagnosis of infant or early childhood mental health or developmental disability or has been assessed to be at-risk for cognitive or mental impairment, or emotional or behavioral disorder. |
| Juveniles referred or under supervision of juvenile caseworkers | 6-20 | Referred for assessment and possible correctional supervision of a juvenile caseworker. |
| Pregnant and postpartum women and those at risk for inadequate parenting | No age criteria | Woman diagnosed to be pregnant by qualified health provider; or gave birth to baby within last 12 months; or have one or more children currently living with them and have inadequate parenting skills. |

| Population Group | Age Group | Eligibility Requirements |
|---|-----------------|--|
| Adults with long-term care needs (DHS) | Age 18 or older | A person who receives in-home services through an agency under contract to the Maine Bureau of Elder and Adult Services (BEAS), or a person receiving or applying for private duty nursing or personal care services through MaineCare, or has applied through MaineCare for a nursing facility level of care. |
| Persons with psychoactive substance dependence (BDS) | | Has been diagnosed with psychoactive substance dependence and currently receives active substance abuse treatment from a BDS-approved provider or receives follow-up or aftercare services. |
| Children and adolescents exhibiting high risk behaviors that may result in social, emotional, or academic failure | Ages 5 to 21 | Described by title. |

Community Residential Services

Many of the licensed residential settings identified in SETTINGS have services associated with those settings. This section describes some of the residential services associated with the residential settings.

*Assisted Housing Programs.*⁹³ In general assisted living services are services provided by a single provider. Assisted Living Services include both housing and assistance with the Activities of Daily Living and Instrumental Activities of Daily Living. Assisted living services may include:

- personal supervision, awareness of resident's whereabouts;
- protection from environmental hazards;
- assistance with activities of daily living;
- administration of medications;
- diversional, motivational or recreational activities;
- dietary services; and
- nursing services.

Assisted living services may be provided in:

- congregate housing;
- adult family care homes; and
- residential care facilities.

⁹³ DHS Rule, 10-144 CMR Chapter 113.

Community Residences for Person with Mental Illness. Mental health treatment programs for adults with mental illness focus on establishing or regaining functional skills; the increase of self-understanding; crisis prevention and self-management; socialization and leisure skill development; the development and enhancement of social roles within the context of natural supports, the community, and the treatment facility; and other activities associated with the individual's rehabilitation goals and objectives. Residential services may include:

- personal care services;
- assistance or supervision of activities of daily living and instrumental activities of daily living;
- supervision of or assistance with administration of medications;
- personal supervision or awareness of resident's whereabouts, to ensure health and safety;
- arranging transportation and making appointments;
- observing or monitoring behavior and reporting changes to providers; and
- integrated treatment services for coexisting disorders of chronic mental illness and addiction disorder, including independent living skills and social skills necessary to promote ongoing recovery.⁹⁴

Community Residences for Person with Mental Retardation. Community residential services for persons with mental retardation provide personal support services in addition to the assisted living services identified above.⁹⁵ Personal support services and residential training services are described below under IN-HOME SUPPORTS.

Residential Substance Abuse Treatment Services. A residential substance abuse treatment facility can provide a range of treatment programs, including:

- residential rehabilitation;
- halfway house services;
- extended care services; and
- extended shelter.

All of these treatment programs include a range of services specific to the purpose of the program. Most of these residential services are of short duration and include assisted living services as appropriate, as well as substance abuse treatment.⁹⁶

Residential Child Care Facilities. Residential child care facilities (RCCFs) provides board and care services for one or more children.⁹⁷ RCCFs provide or arrange health care and dental care services. RCCFs are required to provide access to educational and vocational services. In some cases, a child might attend a community school. If the RCCF provides its own educational services, those services must be in compliance with the same regulations applying to all schools.

⁹⁴ DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 97.

⁹⁵ DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 97.

⁹⁶ DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 97.

⁹⁷ DHS Rule, 10-144 CMR Chapter 101, Chapter II, Section 97.

RCCFs offer licensed substance abuse treatment services or mental health services.

The mental health treatment program includes rehabilitative services intended to improve the individual's instrumental daily living functioning, emotional and physical capability in areas of daily living, community integration and interpersonal functioning. Services include:

- group therapy;
- emotional development skills training;
- daily living skills training;
- interpersonal skills training; and
- community skill training.

The substance abuse treatment program is also focused on rehabilitation. In addition to the physical care, this substance abuse treatment program includes:

- individual and group counseling;
- mental health support or referral;
- vocational, nutritional, recreational guidance;
- family programs;
- didactic presentations and
- planning for and referral to further treatment.

In-home and Personal Services

In-home supports are provided for three different population groups:

- persons with mental illness;
- persons with mental retardation; and
- persons with a physical disability.

In-home supports for each of these groups are described below.

Persons with Mental Illness. In-home supports are covered services for both adults and children with mental health needs.

Adults. Two types of in-home mental health services are covered services for adults, although these services are not widely available. Crisis services are intended to be of limited duration. In-home mental health supports are of longer duration but are still intended to be rehabilitative and, therefore, time-limited.

- *Crisis Intervention and Support Services.*⁹⁸ Crisis intervention services are not necessarily, but may be provided in a person's home. Crisis intervention services include identification and prevention, assessment and screening, intervention, brief counseling, acute treatment planning, problem resolution, clinical consultation, and short-term

⁹⁸ MaineCare mental health crisis services are governed by DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 65.

follow-up. Crisis support services are primarily provided in a person's home or temporary living situation. Crisis support services include monitoring behavior and response to therapeutic interventions; participation and assistance during crisis and post-crisis stabilization activities; and supervisions to assure personal safety. These services may extend for several days.

- *In-home Mental Health Supports.*⁹⁹ In-home mental health supports include personal supervision and therapeutic support services provided to an adult with major mental illness in his or her home or temporary living situation. In-home mental health supports are provided in order to allow a person to maintain the highest level of independence possible. There are two levels of service:
 - *Transitional living skills services.* Transitional services focus on assisting an individual on a short-term (up to one-year duration) basis to learn or further develop those skills necessary or desirable for community living. These services may be provided up to 24 hours per day.
 - *Intensive living skills services.* Intensive living skills services focus on assisting an individual either living in his or her own home or in a shared housing situation (*i.e.*, state licensed supervised apartment, group home, state licensed congregate living program) to learn or maintain skills necessary for independent community living. These services may be required for an indefinite period of time but may change over time to respond to the changing medically necessary needs of the individual. Service goals might include personal supervision for the tasks related to personal skill development, assistance in daily living skills activities, community integration and monitoring of medication.

The continued medical necessity for these services must be reviewed every 90 days. Persons certified as qualified by DHS can provide in-home supports.

Children. Three types of in-home mental health services are available for children. In-home services are funded through the MaineCare state plan and through state-funded programs.

- *Behavioral Health Services.*¹⁰⁰ Behavioral health services are habilitative services provided to a child at home or in a community setting, which focus on behavior management, increased skill development, and physical development activities. The goal is to increase the child's level of function, increase skill development and decrease maladaptive behaviors. Services are provided by a Behavioral Specialist. Behavioral Specialist services are available as long as they are medically necessary.

⁹⁹ MaineCare mental health in-home supports are governed by DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 17.

¹⁰⁰ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 65.

- *Crisis Resolution and Support Services.*¹⁰¹ Crisis resolution and support services can be provided in the home if necessary. Crisis resolution services are available for up to 30 days after the initial crisis event; crisis support services are available for up to 10 days. Crisis support services include monitoring behavior and response to therapeutic interventions; participation and assistance during crisis and post-crisis stabilization activities; and supervisions to assure personal safety.
- *Home-Based Mental Health Services.*¹⁰² Home-based mental health services are short-term, crisis-oriented counseling services provided at home or in another appropriate setting. These services are available to children with mental illness when at imminent risk of removal from the family home or when a child is reunited with a family. (“Imminent risk” means that, in the absence of the services, the child will need an out-of-home placement.) Home-based mental health services are expected to be intensive at the beginning, tapering off over time. The continued medical necessity of these services is reviewed every 30 days, and a clear and compelling rationale for continuing the services must be documented.

Persons with Mental Retardation. Personal support services are the primary in-home support available to persons with mental retardation under the MaineCare Home and Community Based Waivers.¹⁰³ Personal Support Services are administered through BDS and are available to children and adults with mental retardation. Personal Support Services include direct assistance with:

- daily living and personal adjustment;
- household maintenance;
- attendant care;
- assistance with medications that are ordinarily self-administered;
- supervision;
- assistance with ambulation and exercise;
- household services essential to health care at home or performed in concert with assistance of daily living;
- assistance with personal maintenance (such as grooming, bathing, dressing); and
- household maintenance (cleaning, chore services, changing of storm windows, and yard work).

Personal support can be provided in any setting including supported employment. A Personal Support Provider must have training and competency certified by BDS and can be a family member except not a spouse or parent of the individual receiving the services, if that individual is a minor.

¹⁰¹ MaineCare in-home crisis services are governed by DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 65.

¹⁰² MaineCare home-based mental health services is governed by DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 37.

¹⁰³ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 22.

Persons with Disabilities. The following personal and in-home supports are available to persons with disabilities:

- chore services;
- home health;
- homemaker services;
- nutrition services;
- personal care services; and
- private duty nursing.

Each of these services is described below.

- *Chore Services.*¹⁰⁴ Chore services are available to elders and adults with physical disabilities under the MaineCare waivers and the state-funded program administered through BEAS. Chore services include heavy-duty cleaning, raising and lowering combination screens and storm windows, repairs and minor tasks to eliminate safety hazards, lawn mowing and snow shoveling.
- *Home Health Services.*¹⁰⁵ Home health services are available to all age groups through the MaineCare state plan, and to elders and adults under the MaineCare waiver services, and under a state-funded program administered through BEAS. Home health services include:
 - nursing services;
 - physical therapy;
 - occupational therapy;
 - speech therapy;
 - home health aide and certified nurses' aide services; and
 - medical social services.

Under the MaineCare State Plan and the MaineCare Waivers, eligibility for home health services is conditioned on certification from a physician that the individual is homebound or the individual meets the criteria for an exception to the homebound criteria. (“Homebound” means there is a normal inability to leave home and absences from home are infrequent or of short-duration, or are to receive medical treatment or attend adult day services.) Home health services are provided through home health agencies.

¹⁰⁴ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 18, 19 (called “homemaker services” under the waivers); DHS Rule, 10-149 CMR Chapter 5, Section 63.

¹⁰⁵ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 18, 19 and 40; DHS Rule, 10-149 CMR Chapter 5, Section 63.

*Homemaker Services.*¹⁰⁶ Homemaker services are available to elders and adults with disabilities through the MaineCare waiver and through a state-funded program. Homemaker services include:

- routine household care, including sweeping, washing and vacuuming of floors, dusting, cleaning of plumbing fixtures (toilet, tub, sink), appliance care, changing of linens, refuse removal;
- laundry;
- meal planning/preparation;
- shopping, errands, and storage of purchased groceries;
- chore services including, but not limited to occasional heavy-duty cleaning, raising and lowering of combination screen/storm windows, repairs and similar minor tasks to eliminate safety hazards in the environment, lawn mowing or snow shoveling;
- incidental personal hygiene;
- incidental help with dressing; and
- transportation services necessary to perform covered services described in a beneficiary's plan of care, such as medical appointments.

Homemaker services are administered by BEAS and are provided through two private regional providers.¹⁰⁷ For persons receiving other home care services, homemaker services are coordinated through Elders Independence of Maine, the home care coordinating agency for most home support services offered through BEAS.

*Nutrition Services.*¹⁰⁸ Home delivered nutrition services are available to persons who are home or otherwise isolated and unable to prepare a meal. This program is administered by BEAS and nutrition services are provided through local area agencies on aging.

*Personal Care Services.*¹⁰⁹ Personal Care Attendant (PCA) Services are available to children, adults, and elders through the MaineCare state plan, and to elders and adults through the MaineCare waiver services and a state-funded program administered through BEAS and BRS.¹¹⁰ PCA services are available to persons requiring assistance with Activities of Daily Living (ADLs) (bed mobility, transfer, locomotion, eating, toilet use, bathing, and dressing) and Instrumental Activities of Daily Living (IADLs) (meal preparation, grocery shopping, routine housework, laundry, and transportation to carry out the plan of care). Personal care services are available in the home or outside the home.

Eligibility for Personal Care Attendant Services depends on the funding stream. Under the MaineCare State Plan and under the state-funded program, eligibility is based on the need for assistance with ADLs. Under the waiver, a person must be eligible for nursing facility level care

¹⁰⁶ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 18, 19; DHS Rule, 10-149 CMR Chapter 5, Section 69.

¹⁰⁷ Aroostook Home Health and Home Resources of Maine.

¹⁰⁸ DHS Rule, 10-149 CMR Chapter 56, Section 65.

¹⁰⁹ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 12, 40 and 96.

¹¹⁰ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 18, 19; DHS Rule, 10-149 CMR Chapter 5, Section 63 and 73.

in order to be eligible for any services, including PCA services. Eligibility for both children and adults is determined based on the Medical Eligibility Determination assessment tool.

The number of hours per week allowed for PCA services is determined based on estimated time required for the tasks to be performed, with adjustments allowed for extraordinary circumstances. For example, the time allowance for a transfer from bed to a wheelchair is estimated at 5 to 10 minutes.

Depending on the program, PCA services can be provided through agency-based PCAs or through PCAs of the individual's choosing. Programs allowing consumers to hire and fire their PCAs are called "self-directed" programs. A PCA hired under the self-directed program is trained on the job and must demonstrate a level of competency. A PCA hired through an agency must have completed an approved training program. Governed by federal law, all MaineCare programs prohibit hiring a spouse or a parent of a minor to provide PCA services.

*Private Duty Nursing.*¹¹¹ Private duty nursing services are available to all age groups under the MaineCare state plan. Private duty nursing services are provided to a person in his or her residence or outside the residence for "required life activities" (e.g., school, preschool, daycare, medical appointments). Eligibility for private duty nursing is based on an individual's need for specified nursing services at least once per month.

Table 20. In-Home Support Services by Administering Agency: Adults

| Adults | BDS/ MH | BDS/ MR | BEAS | BRS |
|--|--------------------|--------------------|-------------|------------|
| Mental Illness | | | | |
| In-home Mental Health Support Services | ✓ | | | |
| In-home Mental Health Crisis Services | ✓ | | | |
| Mental Retardation | | | | |
| Personal Support Services | | ✓ | | |
| Disability & Elders | | | | |
| Chore Services | | | ✓ | |
| Home Health Services | | | ✓ | |
| Homemaker Services | | | ✓ | |
| Nutrition Services | | | ✓ | |
| Personal Care Assistance Services | | | ✓ | ✓ |
| Private Duty Nursing | | | ✓ | |

¹¹¹ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 96.

Table 21. In-Home Support Services by Administering Agency: Children

| Children | BDS | MaineCare¹¹² |
|---------------------------------------|------------|--------------------------------|
| Emotional Disability | | |
| Behavioral Health Services | ✓ | |
| Home-Based Mental Health Services | ✓ | |
| In-home Mental Health Crisis Services | ✓ | |
| Mental Retardation | | |
| Personal Support Services | ✓ | |
| Disability | | |
| Home Health Services | | ✓ |
| Personal Care Assistance Services | | ✓ |
| Private Duty Nursing | | ✓ |

Table 22. In-home Support Services by Funding Sources: Adults

| Adults | MaineCare State Plan | MaineCare Waiver | Other |
|--|-----------------------------|-------------------------|--------------|
| Mental Illness | | | |
| In-home Mental Health Support Services | ✓ | | |
| In-home Mental Health Crisis Services | ✓ | | ✓ |
| Mental Retardation | | | |
| Personal Support Services | | ✓ | ✓ |
| Disability & Elders | | | |
| Chore Services | | ✓ | ✓ |
| Home Health Services | ✓ | ✓ | ✓ |
| Homemaker Services | | ✓ | ✓ |
| Nutrition Services | | | ✓ |
| Personal Care Assistance Services | ✓ | ✓ | ✓ |
| Private Duty Nursing | ✓ | | |

¹¹² Service is funded through MaineCare and does not have a separate agency responsible for administering services.

Table 23. In-home Support Services by Funding Sources: Children

| Children | MaineCare State Plan | MaineCare Waiver | Other |
|---------------------------------------|-----------------------------|-------------------------|--------------|
| Emotional Disability | | | |
| Behavioral Health Services | ✓ | | |
| Home-Based Mental Health Services | ✓ | | ✓ |
| In-Home Mental Health Crisis Services | ✓ | | ✓ |
| Mental Retardation | | | |
| Personal Support Services | | ✓ | ✓ |
| Physical Disability | | | |
| Home Health Services | ✓ | | |
| Personal Care Assistance Services | ✓ | | |
| Private Duty Nursing | ✓ | | |

Educational Services

*Special Education.*¹¹³ Special education services are provided through the school for children age 5 to 20. School Administrative Units (SAUs) are responsible for administering special education services to all eligible children at no cost. (See PROGRAM ELIGIBILITY CRITERIA above.) SAUs must provide a continuum of special education services to meet the needs of students with disabilities. In addition the SAU must provide supportive services to assist a student with a disability to benefit from the special education services. Supportive services include but are not limited to:

- audiology;
- counseling;
- hearing aids;
- interpreter/transliterators services;
- occupational therapy;
- physical therapy;
- orientation and mobility services;
- parent counseling and training;
- psychological services;
- recreation services;
- rehabilitation services;
- school health services;
- social work services;

¹¹³ DOE Rule, 05-071 CMR Chapter 101.

- assistive technology devices and services including special education equipment (equipment required for participation in program, including wheel chairs, communication aids, computers, ramps, etc.); and
- transportation.

The SAU is responsible for hiring or contracting with service providers to provide these services.

Schools are responsible for providing a continuum of settings for special education services. A school cannot place a child in a residential setting without approval from the Department of Education., after showing that residential services are the best way to meet the child's special education needs.

Children residing in the Elizabeth Levinson Center, the state-operated residential care facility for children with mental retardation, all go to public school programs. Similarly, if children were admitted to the Augusta Mental Health Institute or the Bangor Mental Health Institute, they would receive their education through the public schools. (Currently there are no children in either of these facilities.)

Educational Services for Blind and Visually Impaired Children. Using State funds, the Division for the Blind and Visually Impaired contracts with Catholic Charities Maine to provide educational services to children in schools who are blind or visually impaired. These services include:

- consulting services for parents;
- Braille instruction;
- Braille transcribing ;
- instruction in use of special equipment;
- concept development;
- low vision training;
- activities of daily living;
- vision stimulation programs;
- selection or modification of specialized curriculum;
- instructional strategies to facilitate learning; and
- orientation and mobility skills, etc.

Other Educational Services. In addition to early intervention and special education services, other services are available through the State.

- *The Governor Baxter School for the Deaf.* The Governor Baxter School for the Deaf is a public residential and day school in Maine, serving deaf, hard of hearing children or children with multiple handicaps including deafness. The Baxter School is operated largely independent of the Department of Education and is funded with state dollars.

- *Adult Educational Services.* The Department of Education administers adult education services for persons with disabilities that include instructional services to help adults learn the basic skills relevant to their own goals and needs.¹¹⁴

Early Intervention Services

Several departments provide early intervention services intended to enhance the development of children who have or at risk for disabilities.

*Department of Education.*¹¹⁵ Early intervention services and special education services are provided to children age 3-5 at no cost and early intervention services are provided to children age 0-2 on the basis of a sliding fee scale. Services include:

- audiology;
- developmental therapy/special instruction;
- family counseling;
- family training;
- health services (limited to catheterization, tube feeding, etc.; health status assessment; preventive nursing services; administration of medications, treatments, etc.);
- medical services (for diagnostic or evaluative purposes to determine medically related disability);
- nutrition services (0 to 2);
- occupational therapy;
- parent counseling and training;
- physical therapy;
- psychological services;
- service coordination;
- social work services;
- speech therapy;
- transportation;
- vision services (0-2 only); and
- assistive technology devices and services.

The regional site boards are responsible for developing and monitoring a system for the development, revision and renewal of the IFSP/IEP by the Early Childhood Team. Care coordination for early intervention services is provided through regional Child Development Services agencies. Early intervention services are funded through IDEA, except that MaineCare will pay for covered early intervention services provided to MaineCare eligible children.

Department of Behavioral and Developmental Services. BDS also provides early intervention services for children focusing on children from age birth to three. These services include:

¹¹⁴ DOE Rule, 05-071 CMR Chapter 223.

¹¹⁵ DOE Rule, 05-071 CMR Chapter 180.

- case management services for children from birth to 3;
- developmental therapy;
- infant mental health; and
- infant, toddler, and family supports.

Correctional Services in the Community

The Department of Corrections plays a role in providing or linking individuals (with or without a disability) with community services.

For adolescents, in addition to case management services (through the Juvenile Community Corrections Officers), the DOC also provides or contracts for services. Some of these services include shelter or residential services, supervision and intensive case management services, drug education, work training and counseling, day treatment, and other services. The DOC also works with BDS to link adolescents with needed mental health and substance abuse services.

For adults, probation conditions may include requirements for medical, mental health, substance abuse or sex offender treatment which meets certification standards. Probation conditions might also related to the probationer's residence, employment and education. Probation officers provide a link to community services required as a condition of probation, linking individuals primarily to services funded through other state agencies. Minimal funds are available to pay for community services mandated as a condition of probation that are otherwise not available through other funding.

Independent Living Services

Independent living services are services that assist persons with disabilities in overcoming environmental barriers to functioning independently within a community. For example, home modification services might pay to widen doors or install a ramp for a person who uses a wheelchair. Funding for independent living services derives from the following agencies:

- Bureau of Rehabilitation Services;
- Department of Behavioral and Developmental Services;
- Bureau of Elder and Adult Services; and
- Bureau of Medical Services.

Bureau of Rehabilitation Services. The Bureau of Rehabilitation administers two Independent Living Programs, one for all persons with disabilities and a second for persons who are blind or who have a visual impairment.¹¹⁶ Both programs are funded through the Rehabilitation Services Administration. The independent living services for the broader population is subject to a \$5000 lifetime maximum expenditure. Independent living services include:

- counseling (including psychological, psychotherapeutic, and related services);
- temporary housing and supports;
- home modifications;
- rehabilitation technology;

¹¹⁶ DOL Rules, 12-152 CMR Chapter 7 and 12-150 CMR Chapter 105.

- mobility training;
- services and training for persons with cognitive and sensory and psychiatric disabilities, including life skills training and adult basic education, community orientation, and training in the use of an interpreter and reader services;
- short-term attendant care services incidental to other independent living services;
- assistance in identifying appropriate housing;
- education and training for living and participating in community activities;
- transportation, incidental to independent living services;
- physical and psychosocial rehabilitation;
- therapeutic treatment under the direction of qualified practitioner;
- provision of prostheses and other appliances or devices; and
- individual and group social and recreational services.

The Independent Living Program for persons who are blind also includes:

- rehabilitation services;
- orientation and mobility services;
- Braille instruction;
- low vision services; and
- technological aids and assistive device training.

BRS also administers two programs to assist in acquiring telecommunication devices for persons who are deaf.¹¹⁷ One program pays for half the cost of a telecommunications device and provides training. The other lends the equipment to those who cannot afford to buy it. (To be eligible for the lending program, family gross annual income must be less than 185% of federal poverty guideline for family size.)

These independent living services are provided through AlphaOne, Maine's Independent Living Center.

Department of Behavioral and Developmental Services. Funded through the MaineCare Home and Community Based Waiver, BDS provides environmental modification services for participating persons with mental retardation.¹¹⁸ These modifications or improvements to living quarters are intended to allow for community living and ensure accessibility. Environmental modification services include ramps, lifts, modifications and additions to bathrooms and kitchens, and specialized modifications such as door-widening, grab bars, etc. The waiver also funds adaptive aids (*e.g.*, lifts, control switches, reach extenders) and communication aids (communicators, speech amplifiers, and facilitated communication).

Bureau of Elder and Adult Services. Through a state-funded program, BEAS provides funding for home modifications for elders and adults with physical disabilities. Personal emergency response systems are also funded as a MaineCare waiver service and as a state-funded service.

¹¹⁷ DOL Rule, 12-152 CMR Chapter 12.

¹¹⁸ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 21.

Bureau of Health. The Coordinated Care Services for Children with Special Needs program may authorize the purchase of adaptive equipment and durable medical equipment to eligible individuals.¹¹⁹

MaineCare and Durable Medical Equipment. MaineCare pays for durable medical equipment for persons eligible for MaineCare services living at home and in residential care facilities.¹²⁰

Mental Health Services

The Department of Behavioral and Developmental Services is the lead agency for administering mental health services. (The Bureau of Elder and Adult Services also administers programs that fund mental health services.¹²¹ The Bureau of Rehabilitation Services funds counseling services through its independent living programs.¹²²) Mental health services administered through BDS are available to both children and adults.

In addition to service coordination and the in-home, employment, and housing supports discussed elsewhere, BDS provides other services for both adults and children with mental health needs, including:

- crisis and emergency services;
- day treatment and rehabilitation services;
- outpatient services; and
- other state funded services.

These services are funded through MaineCare state plan¹²³ and through state funds.

Crisis Services. Crisis support services provide assistance to individuals, families, guardians, and providers. Crisis support services can be important to diverting an individual from institutional care.

Day Treatment & Rehabilitation Services. Rehabilitation services aid persons with serious mental illness to improve or recover functional capacity, mastery of activities of daily living, social interaction and work life. Rehabilitation services include vocational, educational, independent living skills, activities of daily living skills, community integration skills, social support activities, social and leisure activities, personal growth activities, and companion or peer partners.

Outpatient Services. Outpatient services are group and individual psychotherapy or other type of mental health treatment which deals directly with the signs and symptoms of mental health problems through prevention, symptom control, and crisis management.

¹¹⁹ DHS Rule, 10-144 CMR Chapter 272.

¹²⁰ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 60.

¹²¹ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 18, 19; DHS Rule, 10-149 CMR Chapter 5, Section 63.

¹²² DOL Rules, 12-152 CMR Chapter 7 and 12-150 CMR Chapter 105.

¹²³ DHS Rules, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Sections 17, 37 and 65.

Other State Funded Services. BDS administers several other state-funded services including social clubs, mobile outreach services for older persons, trauma-informed “warm lines” through sexual assault centers, etc.

For children, additional services include family support and family psycho-education treatment.

Rehabilitation Services for Persons with Brain Injury

The MaineCare program will pay for rehabilitation services for persons with brain injury.¹²⁴ These services include:

- physician services;
- neuropsychologist services;
- rehabilitation nursing services;
- therapeutic recreation specialist services;
- occupational therapist services;
- physical therapist services;
- speech pathologist services;
- social worker services; and
- professional counselor services.

Respite Care and Family Support Services

Respite care services are provided to allow personal time for the individual and the caregiver. Respite care may be provided in the individual’s home or in other locations.

For persons with mental retardation, respite services are provided under the MaineCare waiver, to allow personal time for the regular care-giver and the individual. Respite care services may include room and board, personal care, supervision and skill training.

BEAS also administers respite services for elders and adults with physical disabilities. These services are provided on a short-term basis, because of the absence of, or need for relief of, the caregiver. This service may be provided in the home, in a licensed Adult Day program, or in an assisted living facility; a nursing facility; an acute care or rehabilitation facility; or a facility for the treatment or management of persons who have mental retardation or mental illness.¹²⁵

BDS provides respite care for the families of the children it serves. In addition, BDS provides other family supports, including parent and sibling support groups, and social and recreational activities.

¹²⁴ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 102.

¹²⁵ DHS Rule, 10-149 CMR Chapter 5, Section 68.

Substance Abuse Treatment Services

In addition to the residential treatment services, BDS also offers non-residential substance abuse treatment. The following services are available:

- *Intensive outpatient services* include an intensive and structured program of substance abuse evaluation, diagnosis and treatment services in a setting that does not require an overnight stay.
- *Outpatient care* includes all non-residential services less intensive than intensive outpatient, including substance abuse evaluations, treatment and prevention services, individual and family counseling services.

Other Services for Children

The following are other programs providing services to children with disabilities:

*Services for Children with Special Needs.*¹²⁶ For income eligible children meeting program eligibility criteria (without alternative public or private funding), the Bureau of Health offers assistance with the coordination of care and referral services and administers funding for diagnostic, evaluation and treatment services related to the specific condition upon which eligibility is based.

*EPSDT.*¹²⁷ The MaineCare program funds Early and Periodic Screening, Diagnosis, and Treatment Services (EPSDT) for MaineCare eligible children. The EPSDT benefit provides:

- screenings for physical health needs, hearing and vision, lead poisoning, developmental and behavioral services, etc.;
- eyeglasses, hearing aids, other treatments for hearing or vision loss;
- dental care;
- any other services necessary to correct or ameliorate physical or mental illnesses, etc., as covered by MaineCare; and
- other services not governed by MaineCare rule but determined to be medically necessary and meeting other prior authorization requirements.

Other Services for Persons with Mental Retardation

In addition to the services mentioned elsewhere (including those discussed in the housing and development services sections) in this document, the MaineCare waiver¹²⁸ provides for the following services for persons with mental retardation:

Day Habilitation Services. Day habilitation services are provided outside the home and include training in intellectual, sensory, motor and affective social development. Day Habilitation services are also funded under the MaineCare state plan.¹²⁹

¹²⁶ DHS Rule, 10-144 CMR Chapter 272.

¹²⁷ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter V, Section 2.

¹²⁸ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 21.

¹²⁹ DHS Rule, 10-144 CMR Chapter 101, MaineCare Benefits Manual, Chapter II, Section 24.

Crisis Intervention. Crisis intervention services include consultation with providers, families and the individual to develop, monitor and reassess behavioral or treatment plans; providing direct intervention in a crisis situation.

Consultation Services. Consultation services are services which assist parents and providers in carrying out the individual care plans.

Other Services for Persons with Disabilities

Through the Bureau of Elder and Adult Services, the following services are offered, in addition to those mentioned elsewhere in this document:

*Adult Day Health.*¹³⁰ Adult day services are funded under the MaineCare state plan, under the MaineCare waivers and under the state general-fund programs. Adult day health services provide assistance with activities of daily living; snacks and a meal; activities, socialization and stimulation; transportation services necessary to perform activities and socialization services; and transportation services necessary to transport a consumer to the program and return home (last resort).

Adults in Protective Custody. For elders and adults in protective custody, some funds are available to meet short term needs, when other funding sources are not available.

Waiting Lists

Describing the array of services offered by state programs can be misleading without recognizing that not everyone identified to be in need of services is actually receiving them. Whether because the funding is not available or the provider is not available, some people are on waiting lists for needed services. The length of wait will vary depending on the service, but in some cases the wait can be as long as years. Whenever possible, alternative services are provided in the interim. However, the waiting period can mean that advances are lost or that health status worsens.

Waiting lists are a difficult, yet critical, subject to address in this document. The trigger for litigation, waiting lists should be reliable evidence that needs are unmet. Collecting accurate information on waiting lists is important for making sure the State is meeting the needs of individuals on the waiting list and for identifying systemic opportunities for improvement.¹³¹ The State also needs to make sure that people on waiting lists are treated fairly and move up the waiting lists according to a rational priority system.

¹³⁰ DHS Rule, 10-149 CMR Chapter 5, Section 61.

¹³¹ Waiting lists are also important under the *Olmstead* decision. Under the *Olmstead* decision, a state can defend a claim that it is violating the ADA if it has a comprehensive, effectively working plan for placing people in less restrictive settings and, if a waiting list is necessary, it moves at a reasonable pace, not controlled by the state's attempts to keep its institutions full. Thus, to avail itself of this defense, a state that has a waiting list for services in a less restrictive setting must be able to show that it has a fairly administered waiting list moving at a reasonable pace. Some would argue that demonstrating fair administration of a waiting list would require a state to have a fair process for administering waiting lists and to collect minimum information about who is on a waiting list, why, and the expected wait.

For entitlement programs (*e.g.*, MaineCare and special education), the State cannot have waiting lists if the eligibility criteria are met -- a person that meets the eligibility criteria is automatically in the program. Waiting lists are possible, however, for non-entitlement programs. In those cases, the wait results because funding is not available. For example, people who are eligible for MaineCare waiver services might need to wait for a slot to open up if all slots are filled. People might also be on a waiting list for state-funded programs, which are often capped by available resources.

A person might be on a waiting list to receive a service, whether provided through an entitlement program or not. The primary reason for service waiting lists is the shortage of providers available. A person might be put on a waiting list for services at any one of three points in the process:

- A person may have requested a service or a different setting but the need for that service or alternative setting has not been confirmed.
- The need for a service in a more integrated setting may be identified, but there is no provider or setting identified to provide the service.
- A person is on a list to receive a service or move to an alternative setting but must wait for an appointment.

Collecting and maintaining accurate waiting list data is challenging. There are no standard definitions for waiting lists. Some programs require providers to keep waiting lists and have established a priority system for moving people up waiting lists. Others do not have clear standards about where in the process one is considered to be on a waiting list or how frequently the list needs to be updated. Others do not keep waiting lists at all. (For special education providers, it is against the law to have a “waiting list,” although people do wait for services when there is a provider shortage.) Adding to the confusion a person might be on a waiting list with multiple providers.

Information and Information Systems

Information and information systems are tools for using resources as efficiently and as effectively as possible. Information and information systems are also tools for evaluating the effectiveness of services. Information is required for operating and evaluating each of the independent service systems described in this document. Information is all the more important when attempting to coordinate across these systems. This section describes the different roles information plays in supporting services to persons with disabilities, the kinds of information currently collected, and other related issues.

The *Olmstead* decision creates heightened need for certain types of information and for integration of information across programs and departments. For example, in the context of *Olmstead*, the State has a need to know what the level of service need is, whether the level of service is offered in a more integrated setting, whether that individual prefers living in a more integrated setting. The State also has an increased need for data analysis. An agency might want to analyze data to identify systemic barriers to integration. Are people not moving to more integrated settings because of a shortage of providers? With this information the State can take steps to address systematic barriers to integration.

Uses of Information Systems

Information systems support two primary functions.

Operational. Information systems are created to support the primary operations of a state agency or program. For example, the Bureau of Medical Services (BMS) is responsible for processing MaineCare claims. To that end, the information BMS collects focuses on the services provided, who provided them, to whom, and other information pertinent to whether or not the claim should be reimbursed and how much should be paid. The Bureau of Child and Family Services (BCFS), on the other hand, provides service coordination. BCFS' information system supports the service coordination function, collecting personal characteristics and demographic information, assessment and plan elements, and so on.

Analytical. Information systems are also used to evaluate the effectiveness of services, to manage resources, or to comply with a law, consent decree, etc. An agency might want to evaluate data to identify people that go through the “revolving door” from institutional setting, to home, back to an institutional setting. How many people experienced this cycle? Were there common characteristics that could be addressed to reduce the number of returns to the institutional setting? Or perhaps an agency will decide to reallocate funding after it discovers that people are using a more expensive service, like emergency room services, because less expensive alternatives are not available. If less expensive alternatives are used, the agency will want to use data to analyze whether or not those alternatives result in different outcomes. In other cases, an agency might be required to produce reports, by a funding agency, the Legislature, or a court. The information collection practices within both the Department of Education and the Bureau of Rehabilitation Services are shaped by federal reporting requirements. BDS has also created information systems to support compliance reporting for consent decrees.

Types of Information Collected

As with every other aspect of operations discussed in this document, the information collected is driven largely by the different needs and responsibilities of the agency collecting the data. As discussed above, the different operations of an agency will dictate the focus of the information systems. In addition, governing statute, whether state or federal, may also govern the types of information collected.

Collected information might include information about people served (including identifying information, characteristics, and demographics), providers, assessments, care plans, services, etc. A sampling of some of the data resources available includes:¹³²

Behavioral and Developmental Services. BDS is currently building its information system as a “module” of the BMS MaineCare systems. The BDS system will collect the following information:

- client information for all individuals receiving BDS services;
- provider information;

¹³² This information is derived from *Roadmap for Data System Integration*, Tan and Griffin, Edmund S. Muskie School of Public Service (November 2001).

- relevant, limited plan information;
- relevant, limited assessment information;
- relevant, limited service encounter information;
- program authorization information (e.g., waiver program authorizations);
- financial information; and
- information required to support the operations of state-run state mental hospitals and state residential facilities.

Corrections. The DOC collects data on the level of need identified through assessments, the treatment plan, and whether or not that person is in treatment. The DOC has recently issued a request for proposals to develop and implement an automated offender management information system for its central office, adult institutions, adult community corrections, juvenile institutions, and juvenile community corrections. The new information system will, among other things, collect information on programs and treatment, including treatment plans for adults and juvenile inmates, as well as interventions, assessments, MaineCare claims, etc. for juveniles on probation.

Education/Division of Special Services DOE collects data for federal reporting requirements, including the number of students with disabilities by age, type of disability, and placement, services and exit data. DOE collects financial data on special education expenditures. For children placed out of the school administrative unit, DOE collects information on the student's disability, age, where the child is placed and the cost of the placement and the reason for the out-of-district placement.

DHS, Bureau of Child and Family Services (BCFS). Through the Maine Automated Child Welfare Information System (MACWIS), BCFS records and tracks all case management activity. MACWIS data includes information on the children it serves, along with other people connected to the case; and providers licensed by BCFS, including residential child care facilities, foster homes and shelters.

DHS, Bureau of Elder and Adult Services (BEAS). BEAS collects an electronic version of its assessment tool, creating the MECARE database. MECARE collects demographic, clinical, caregiver and environmental information. MECARE data is collected for some of MaineCare long-term care state plan services, waiver services and services provided under the State's Home-based Care Program. BEAS also collects data on expenditures on home care and home-based care expenditures.

DHS, Bureau of Medical Services (BMS). BMS collects MaineCare claims data as well as some linked Medicare and MaineCare claims data. The MaineCare data includes:

- claim (professional and institutional) information;
- prescription claims information;
- enrolled provider information;
- enrolled member information;
- prior authorization information;
- related demographic information;
- related birth & death information;

- related financial/budget information;
- MaineCare managed care information (e.g., capitation rates, etc.); and
- licensure information (e.g., Certified Nursing Assistant information).

Labor/Bureau of Rehabilitation Services (BRS). BRS maintains data on the people it serves including demographic data, disabling condition, categorical information on services received, status within service system, and outcome of service. Data on the cost of services and service providers is also available.

Limitations of Existing Data Resources

Data Sources. The State’s data resources are limited by the data collected by different data sources. Some data are collected from sources outside the direct control of the State, such as schools or providers. These independent data sources will not necessarily be at the same stages of automating data collection, or have the same standards (or definitions) for data collection. The State has some ability to influence the automation, collection and standardization of data collected from independent sources, either by incentive (e.g., reimbursement) or regulation (e.g., reporting requirement).

Linked Data. The State, in general, cannot link data collected for one department with data collected from another department. From the “operational” perspective, the State’s ability to serve people is impaired because the State does not have a complete picture of an individual’s needs across all of the programs serving that individual. A person might be served by four departments and none need know about the others. From the “analytical” perspective, the State is not able to capture a complete picture of how it is using its resources or evaluate the effectiveness of services. For example, the State has no way of producing an un-duplicated count of how many people it serves.

Comparability. Because each department has different functions, with different authorizing statutes, each department will collect different data using different language and definitions. For example, because eligibility is different across programs, some types of information will matter more to some departments than to others. For example, eligibility for MaineCare does not necessarily depend on determining whether an individual has a disability, so MaineCare does not collect information about the presence of or type of disability (although this information can be inferred in some cases). For Special Education, on the other hand, eligibility is based on whether a child meets the specific criteria for one of several types of disabilities. As a result, DOE collects information about the presence of a disability and the type of disability, using its own definitions, which may or may not match those definitions used by another department.

Quality Management

Quality management is key to assuring that the State's plans for providing home and community based services are effective and achieving desired outcomes. This section reviews the different quality management systems in place across departmental programs.

For the purposes of this document, quality management is divided into four functions:

- setting standards;
- compliance;
- performance measurement; and
- quality improvement initiatives.

Setting Standards

As discussed earlier (THE ROLE OF STATE GOVERNMENT), the State can shape the quality of services and providers by setting standards. Generally, standards define the “inputs” or structure for a service, facility or provider. For example, standards will define training requirements for providers or the type and number of providers for a program. Standards will define required policies and procedures, documentation standards and consumer protections.

Standards are established through a variety of mechanisms, including licensing regulations, program regulations, and regulations and contracts governing reimbursement. TABLE 24 identifies the different methods the departments use for defining standards.

Compliance

Ensuring compliance with standards is another part of quality management. A department can ensure compliance through a variety of methods. TABLE 25 identifies the different methods the departments use for ensuring compliance with the standards they establish.

Performance Measures

A performance measure is intended to measure the effectiveness of a program or service: what are the benefits derived from the money spent (*e.g.*, increased employment, better health, etc.)? Over the past decade federal agencies providing funding for state programs have placed increasing emphasis on measuring the outcomes of the services provided. For example, federal funding for both rehabilitation services and special education is now conditioned on submission of performance measures developed by the state agencies administering those programs.

Measuring performance is easier where an agency can identify the relationship between the agency's actions and an intended outcome. For example, the Bureau of Rehabilitation Services can measure how many cases it has closed after a person has successfully maintained employment for 90 days. However, it is more challenging to measure the success of, for example, in-home supports or independent living services. Presumably the benefit of these services is measured in terms of the quality of life they provide. The impact a service has on the quality of life, independence, or the degree of “integration” into the community are difficult to capture.

Because of the variation in the ability to measure, state agencies are in different stages in measuring performance. However, as the federal government continues to provide direction, it is anticipated that the State's ability to measure performance will evolve and improve.

Quality Improvement Initiatives

Like performance measures, quality improvement initiatives are in different stages of evolution across agencies, depending on the quality measures. For example, for MaineCare services, the Physician Incentive Payment program gives feedback to providers serving MaineCare beneficiaries identifying opportunities for improving the quality of care provided. However, because it is more difficult to measure quality (and, thus, opportunities for improvement) it is more difficult for the MaineCare program to provide feedback to providers of long term in-home services. TABLE 24 describes some of the State's qualitative improvement initiatives.

Table 24. Examples of Quality Improvement Initiatives

| Department | Quality Improvement Programs |
|-------------------|---|
| BDS | Review of measures internally and regionally with recommendations to BDS' Central Office executive management team. |
| DOC | Quality improvement efforts may come from internal reviews of facilities and subject matter areas, may be dealt with by specific subject matter staff such as medical or safety staff, or may be the result of audits and accreditation efforts through the ACA. |
| DOE | Learning Results will be able to measure progress in decreasing the number of students taking alternative assessments. |
| DHS | Feedback to physicians on quality and types of care provided; BEAS conducts provider survey and requires EIM to conduct survey, provides feedback to providers; BEAS requires EIM to convene regional Quality Assurance Review Committees (QARCs) responsible for recommending policy changes, reviewing randomly selected cases, and making recommendations for improving quality of care and outcomes for the consumer. |
| DOL | Customer satisfaction survey data will go to every individual whose case is closed. Central office staff continues to develop internal measures of quality. |

Table 25. Standards for Service Delivery

| Standards | BDS | DOC | DOE | DHS | DOL |
|-----------------------------|--|---|---|---|---|
| Services or Programs | Defined by BDS rules, MaineCare rules, and contracts | Services are governed by constitutional requirements, state law, accreditation standards set by the American Correctional Association, and internal policy. Standards for medical services are written into contracts with providers; | DOE regulations set standards for special education programs for both public and private schools | Defined by DHS rule | Defined by state and federal rules |
| Necessity | | | DOE standards govern the educational necessity of services | MaineCare and BEAS rules govern the medical or functional necessity of services | Necessity of independent living services and vocational rehabilitation services defined by rules. Rules define medical or functional necessity of personal care services. |
| Reimbursement | DHS MaineCare rules and BDS contracts govern. | Provider contracts, depending on scope and subject of transaction. | DOE regulations identify qualified personnel eligible for DOE subsidy (special education/ supportive service) | DHS MaineCare rules and DHS contracts govern | |
| Facilities | BDS and BMS regulations and national accreditation standards | Facilities are state operated, governed by policies and procedures. DOC is bringing the facilities into compliance with ACA standards. | Standards for schools set by DOE | Licensed by DHS rule | NA |

| Standards | BDS | DOC | DOE | DHS | DOL |
|-----------------------------|--|--|---|--|--|
| Other Providers | BDS licenses agencies. Other providers licensed by professional boards, registered | | Certification standards for teachers, educational technicians, etc. set by DOE; | DHS licenses agencies. Other providers licensed by professional boards, or registered with DHS | Joint rule with BDS requiring any employment service provider or day program to obtain accreditation from Commission on Accreditation of Rehabilitation Facilities (CARF). |
| Consumer protections | BDS rules govern rights of recipients | DOC rules govern grievances, discipline, etc., including advocate system | DOE rules govern appeals, rights, etc. | DHS rules govern rights; state law governs capacity and incapacity and termination of parental rights. | DOL rules govern appeals and rights. The Client Assistance Program provides advocacy. |

Table 26. Methods of Ensuring Compliance

| Review | BDS | DOC | DOE | DHS | DOL |
|--|--|--|---|---|--|
| Periodic examinations and site visits | DHS conducts periodic onsite examination of facilities. BDS conducts site examination on as needed basis or every 3 years. | Conducted by DOC and pursuant to audits by ACA. | DOE regulations require an onsite review of each school administrative unit and special purpose private school (every 5 years) and regional board (every 2 years). | DHS conducts periodic onsite examination of facilities. BMS conducts record review for MaineCare providers. BEAS staff conduct site visits and record review for Goold and EIM. | As part of CARF accreditation renewal every 3 years. |
| Provider license renewal or disciplinary action | Periodic renewal of licenses, disciplinary actions by licensing boards. | Periodic renewal of licenses, disciplinary actions by licensing boards. | Teachers and other educational professionals recertified every 5 years; other licenses governed by boards. Schools hold records of licenses and certification. Certified personnel subject to discipline at local or state level. | Periodic renewal of licenses, disciplinary actions by licensing boards. | CARF accreditation required; if lose accreditation, lose ability to conduct business with BRS. |
| Data & Reports | Contracted providers submit reports on financial, staffing and service data. | Contracted providers submit reports on financial, staffing and service data. | School financial reports; federal reporting requirements. | Contracted providers submit reports on financial, staffing and service data. | Contracted providers submit reports on financial, staffing and service data. Performance data under accreditation program. |

| Review | BDS | DOC | DOE | DHS | DOL |
|---|-------------------------------|--|---|---|---|
| Utilization/ Decision review | Utilization review nurse | | School administrative units review eligibility and utilization on annual or 3-year basis. DOE reviews all out-of- district placements. | Bureau of Medical Services reviews certain MaineCare services subject to prior authorization and conducts retrospective review for some services. BEAS' Quality Assurance Review Committee conducts random reviews for in- home support services. | NA. |
| Due Process and Appeals | Formal grievance procedure | Three step formal grievance procedure | <ol style="list-style-type: none"> 1. mediation/complaint due process 2. state court 3. federal court | <ol style="list-style-type: none"> 1. MaineCare member services 2. appeal process 3. review by commissioner 4. appeal to court | <p>Informal negotiation precedes formal process:</p> <ol style="list-style-type: none"> 1. mediation 2. administrative hearing 3. review by commissioner 4. appeal to court |

Housing

Like most people without disabilities, many people with disabilities would like the option of living in a private residence, perhaps a single-family home in a residential neighborhood or in an apartment or condominium. However, addressing the housing needs of people with disabilities is complex. First, because people with disabilities are often poor, the availability of affordable housing is critical. Second, many people with disabilities need services as part of daily living; those services need to be provided in whatever setting they live. Third, for many people with disabilities, different barriers limit the range of housing options available. The barriers might be physical barriers, communication barriers, negative attitudes toward individuals, or resistance to making accommodations.

Matching the complexity of the need is the complexity of the systems in place to address those needs. Multiple federal, state and local programs attempt to address the affordability of housing, both for the general population and for people with disabilities. Multiple programs also promote residential services for persons with disabilities. Both the federal and state government have enacted a number of laws governing civil rights and the construction of housing.

Without attempting to be exhaustive, this section describes the different systems and laws in place to address the housing needs of persons with disabilities. Here we outline:

- the multitude of participants in the delivery of housing services;
- affordable housing programs; and
- fair housing laws.

Housing: Who is Involved?

Many different entities play a role in determining the nature, the availability and the affordability of housing for persons with disabilities:

- the federal government;
- state agencies;
- Maine State Housing Authority;
- public housing authorities;
- developers and funders;
- non-profit organizations;
- landlords; and
- consumers.

Following is a brief summary of the role of each of these parties.

The Federal Government

Multiple federal departments play a role in creating or shaping the housing options available to persons with disabilities. The U.S. Department of Housing and Urban Development (HUD) and the U.S. Department of Agriculture (USDA) both fund housing development. HUD also funds housing assistance (rental and homeownership subsidies). The Centers for Medicare and Medicaid Services and the Administration on Aging, both within the U.S. Department of Health and Human Services (HHS), sets standards for and fund supportive services. The Rehabilitation Services Administration, within the Department of Education, funds independent living and adaptive equipment services. The U.S. Department of Treasury oversees implementation of the Community Development Financial Institutions Fund, the Community Reinvestment Act, and the Low Income Housing Tax Credit.

State Government

Several state agencies play a role in influencing where people with disabilities live. The Department of Behavioral and Developmental Services (BDS) and the Bureau of Elder and Adult Services (BEAS), within the Department of Human Services (DHS), both administer programs that provide residential services and in-home services. BEAS also licenses residential facilities providing services to adults. The Bureau of Medical Services (BMS), also within DHS, provides MaineCare funding for support services. The Community Support Services (working for both BDS and DHS) licenses residential facilities providing services to children. The Bureau of Rehabilitation Services (BRS), within the Department of Labor, administers independent living and adaptive equipment services, and now the self-directed personal assistance services. The Department of Economic and Community Development administers HUD's community development block grant.

The Finance Authority of Maine (FAME), an independent state agency, also plays a role. FAME houses the Family Development Account Program and the MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program. The Maine Human Rights Commission enforces fair housing law under the Maine Human Rights Act.

Maine State Housing Authority (MSHA)

The Maine State Housing Authority (MSHA) is a statewide housing authority. While created by statute¹³³ and given some of the authority and responsibility of a state agency¹³⁴ MSHA is not part of state government. MSHA has broad responsibility for promoting, financing, and coordinating housing development.

HUD requires MSHA to develop a Consolidated Plan that documents the affordable housing needs for Maine and describes how HUD resources will be used to address those needs over a five-year period. The plan must be developed with public input, including input from people with disabilities and advocates.

¹³³ 30-A M.R.S.A. § 4722.

¹³⁴ *E.g.*, MSHA can accept federal funds on behalf of the State and is required to make certain rules in accordance with the State's Administrative Procedures Act.

The Maine State Housing Authority may not operate in any area in which a local public housing authority has been established, without the consent of the local authority.¹³⁵ In those areas without a local public housing authority, MSHA operates through local agents.

| MSHA Local Agents | Counties Served |
|---|--|
| Aroostook County Action Program | Aroostook |
| Dirigo Housing Associates | Kennebec, Lincoln, Sagadahoc |
| Community Concepts, Inc. | Androscoggin, Franklin, Oxford, Somerset |
| Penquis Community Action Program | Penobscot, Piscataquis, Waldo, Knox |
| York-Cumberland Housing Development Corp. | Cumberland, York |
| Washington-Hancock Community Agency | Washington, Hancock |

Public Housing Authorities

Pursuant to state statute, each municipality in the state may authorize a local public housing authority (PHA).¹³⁶ The powers and duties of the PHAs are set forth in statute and include analyzing municipal housing needs and operating housing projects.¹³⁷ In Maine there are 25 community and five tribal public housing authorities.¹³⁸ Of the people served by Maine's PHAs, 26 percent are under the age of 62 with a disability, and 11 percent are over age 62 with a disability.¹³⁹

PHAs are independent of, but receive most of their funding through HUD and MSHA. The PHA determines which funding to pursue.

A PHA must submit a five-year plan to HUD describing how it will use its public housing resources to meet the housing needs of low-income families. The PHA must include public input in its planning process.

¹³⁵ 30-A M.R.S.A. § 4702(1)(C).

¹³⁶ 30-A § 4721(1).

¹³⁷ 30-A M.R.S.A. §§ 4741-47.

¹³⁸ These housing authorities include: Aroostook Band of Micmac, Auburn, Augusta, Bangor, Bath, Bar Harbor, Biddeford, Brewer, Brunswick, Caribou, Ellsworth, Fort Fairfield, Houlton Maliseet, Indian Township Passamaquoddy, Lewiston, Mount Desert, Old Town, Penobscot (Indian Island), Pleasant Pt. Passamaquoddy, Portland, Presque Isle, Saco, Sanford, South Portland, Southwest Harbor, Topsham, Tremont, Van Buren, Waterville, and Westbrook.

¹³⁹ *The State of Maine's Housing 1999*, Maine State Housing Authority.

Developers and Funders

A developer is someone who takes responsibility for acquiring the funding and property, and then building (or renovating) affordable housing. A developer can be a for-profit or non-profit organization, although the affordable housing market does not usually attract for-profit developers. The developer works with a range of funding sources to bring the necessary funding together.

In addition to federal and state housing programs, funders can be private lenders, local communities, investors, etc.

Fannie Mae and Freddie Mac are private companies operating under a congressional charter. Both companies were created to make homeownership more affordable to low- and moderate-income borrowers. They are able to do so because of their lower costs and larger scale, both products of their government charter. Neither lends money directly to home buyers. Instead they purchase mortgages from lenders in an effort to ensure the availability of mortgage credit to low- and moderate-income home buyers.

Non-Profit Services Organizations

Non-profit service organizations can play a number of roles. A non-profit might provide services in a residential facility or in-home supports. A non-profit might also be the developer or owner of the housing, acting as landlord as well as the provider of services. In some cases, a non-profit services organization might choose to become a Community Housing Development Organization (CHDO). CHDO is a term recognized under HUD's HOME program, discussed below. One-third of the CHDO's governing board must include or represent residents from low-income neighborhoods or communities.

Landlords

Landlords play a significant role in determining the availability of accessible and affordable housing. A landlord might rent one or two units on the side or multiple units as a primary business. Landlords can decide whether or not to accept rental assistance from a potential tenant. Or they can enter into agreements with a housing authority to designate some units as subsidized housing. Landlords might have little or no experience with renting to persons with disabilities or the landlord might be in the business of providing services to persons with disabilities.

Consumers

Different people with different disabilities will have different needs that must be accommodated in order to provide meaningful housing choices. Some people with disabilities are unemployed or low income, so are more likely to need affordable, possibly subsidized, housing. Some people are more likely to experience barriers to housing, whether physical or otherwise, so will need accommodations. Some people will need support services in their home to help them with the activities of daily living and other needs. And many people will have different preferences for where they want to live. A consumer might prefer to live in a typical community setting, integrated among people without disabilities. Or a consumer may prefer to live in a home with other people having similar needs. For many people, the choice of where to live will be influenced by the need to access transportation, employment and other services.

Affordable-Housing Programs

There are multiple programs that support affordable housing. Some of these programs are rental assistance programs; some subsidize building, repairing, acquiring or operating affordable housing; some promote homeownership. Some programs are operated by the federal government and others by state and local entities and other sources. Some programs are targeted to people with disabilities and others are targeted at the general low-income population. The next few sections describe:

- the process of developing affordable housing;
- affordable housing programs for people with low-incomes;
- affordable housing programs for people with disabilities;
- rental assistance programs; and
- homeownership and home modification programs.

Developing Affordable Housing

As described in the next few sections, improving the availability of affordable housing offers a series of challenges. For almost every housing program, multiple parties can play a role. These parties include public agencies or instrumentalities, including federal, state or local government, and housing authorities, and private sector parties, including lending institutions, developers, and landlords. The complexity of these relationships, the funding streams, and the systems of accountability, is itself a barrier to addressing housing needs.

Housing for people with disabilities crosses a spectrum of settings, including residential care facilities, residential child care facilities, adult family care homes, foster homes, congregate or independent housing, and private homes and apartments. (These residential options are described in SETTINGS under HEALTH, MENTAL HEALTH, AND SUPPORT SERVICES.) Each of these settings offers different levels of supports and services, as well as a varying degree of control over personal space and activities. In a residential treatment facility, bedrooms might be semi-private with other living space common to all residents. In congregate housing, residents typically have their own apartment with the option to share common areas and activities with other residents. Support services are offered in all settings, with the less private settings serving people with the highest level of need.

To develop affordable housing for people with disabilities, a developer has to be fairly sophisticated at accessing affordable housing funds. This process is usually too cumbersome with too few financial rewards to attract for-profit developers. Some non-profit organizations serving people with disabilities have the resources and expertise to act as their own developers, putting together their own housing development projects. Smaller service organizations that want to develop housing are likely to rely on an independent developer. Community Housing of Maine and CEI, Inc. are non-profit organizations that have served as developers for multiple public housing projects.

HUD and MSHA both look more favorably on proposed housing projects with multiple funding sources. Funding sources and types of funding can be diverse. In addition to state and federal funding sources, local and private entities may provide funding. The Federal Home Loan Bank

of Boston and Fannie Mae and other lenders play active roles in funding affordable housing. The Maine Housing Investment Fund is a non-profit organization that provides equity to affordable housing developments by purchasing Low Income Housing Tax Credits. Public funding sources supply capital, sometimes operating subsidies, and sometimes rental assistance for low-income tenants. Some funding may be a contribution. For example, a local community might help to fund a project by donating land or a tax payment that would otherwise be due. Or a bank might contribute funds by giving a break on the interest rate.

When there are multiple funders, there is sometimes competition for priority. In addition, different funders will have competing or inconsistent requirements. For example, different funders will require a certain percentage of rental properties be allocated to low-income tenants. Managing compliance with these constraints will require a certain amount of expertise. Again, in Maine, only a few service organizations have that expertise (*e.g.*, Shalom House). In other cases, the service organization might be the landlord but will hire a third party, such as Community Housing of Maine or CEI, Inc., to manage compliance.

Housing funds can be used to produce the physical structure for supportive housing but other funding sources are required for the services. MaineCare funding is the biggest source of funding for support services, with other funds coming from the Administration on Aging and state funding. The supportive services offered in residential settings and at home are described in COMMUNITY RESIDENTIAL RESOURCES, IN-HOME AND PERSONAL SERVICES, and INDEPENDENT LIVING SERVICES.

Sometimes, organizations can creatively avoid some of the complexity of the affordable housing programs. In at least one case, a non-profit service provider has been able to work with private, non-profit developers, using private lenders, to develop housing for people with disabilities. By using private lenders, the private developers avoided the bureaucratic application process, as well as the regulatory requirements imposed by public funding. The newly constructed housing was then rented to the non-profit. The non-profit guarantees the developer, now the landlord, full occupancy. That means that the developer/landlord is spared the responsibility of seeking tenants, but has a steady income stream. The non-profit organization has the incentive to provide the supports necessary to maintain continuity in tenants.

In another example, state funds were used to pay for supportive services in a congregate housing demonstration partly to avoid the complicating requirements of the federal Medicaid program.¹⁴⁰

Affordable Housing Development for People with Low Income

Numerous programs provide funding to increase or maintain the stock of affordable housing. These programs are administered by HUD, the USDA, the Department of Treasury, MSHA, and the Maine Department of Community and Economic Development. Some of these programs provide capital to develop, acquire or rehabilitate affordable housing. Some subsidize operation of affordable housing. Some subsidize home modification. Many programs target the general low-income population. Others target people with disabilities. Many affordable-housing

¹⁴⁰ Bolda, et. al., *Creating Affordable Rural Housing with Services: Options and Strategies*, Edmund S. Muskie School of Public Service, April 2000.

programs designed for people with low incomes also serve people with disabilities. In a number of instances, people with disabilities meet eligibility requirements for both kinds of programs.

Housing development programs that serve people with low-income include the:

- HOME Investment Partnership Program;
- Community Development Block Grants;
- Direct Loan Program;
- Guaranteed Loan Program;
- Low Income Housing Tax Credit;
- Community Reinvestment Act;
- Community Development Financial Institution Fund;
- New Lease Program; and
- Rental Loan Program.

Other housing development programs provide funding to develop housing for people with disabilities. These programs are discussed below.

HOME Investment Partnership Program. Funded through HUD, the HOME Investment Partnership Program provides funds to state and local governments to enable them to develop housing for low-income people. These funds may be used to acquire real property and construct new housing for rent or ownership; to enable low-income homeowners and homebuyers to rehabilitate or purchase homes through direct loans, assistance with down-payments or closing costs, and loan guarantees; or to assist tenants with security deposits and rental subsidies.

Forty percent of HOME funds are allocated among the states while the remaining 60 percent are allocated among cities, urban counties, and legally bound consortia of contiguous, non-urban units of local government. The allocations are based on a formula that considers the inadequacy of the housing supply; the supply of substandard rental housing; the number of low-income families in rental housing units in need of rehabilitation; the cost of producing housing; the incidence of poverty; and the fiscal capacity to develop without federal assistance. All states receive a minimum of \$3 million annually. All units of local government receive a minimum of \$500,000 annually; however, units of local government are required to raise \$250,000 in local funds during the first year. Every federal dollar spent on affordable housing must be matched by 25 cents in local funds.

The nature of the funded activity determines who can benefit from HOME assistance. For rental housing and rental assistance, at least 90 percent of benefiting families must have incomes that are no more than 60 percent of the HUD-adjusted median family income for the area. In rental projects with five or more assisted units, at least 20 percent of the units must be occupied by families with incomes that do not exceed 50 percent of the HUD-adjusted median. The incomes of households receiving HUD assistance must not exceed 80 percent of the area median. HOME-funded housing units must remain affordable in the long term (20 years for construction of new rental housing or 5 to 15 years for construction of homeownership housing and housing rehabilitation, depending on the amount of HOME subsidy).

A non-profit organization can be certified as a Community Housing Development Organization (CHDO) if its primary purpose is to provide and develop affordable housing in its community. A CHDO may serve as owner, developer or sponsor of a housing project; and receive predevelopment loans and technical assistance or operating funds. It can build, acquire or rehabilitate rental or homebuyer property. State and local governments that receive HOME funds are required to set aside annually 15% of those funds for CHDO activities.

Community Development Block Grants. Community Development Block Grants are annual direct grants to states or large urban centers. In Maine, the Community Development Block Grant is administered by the Office of Community Development within the Department of Economic and Community Development. Under the grant, the Housing Assistance Grant Program provides funding to address housing problems of low and moderate income persons. Eligible activities are those directly related to assisting or creating residential housing units including acquisition, code enforcement, conversion of non-residential structures, demolition, historic preservation, housing rehabilitation, new housing construction, relocation assistance, and removal of architectural barriers. The maximum amount for a Housing Assistance program grant award is \$400,000. The Housing Assessment Planning Grant Program provides funding to communities or community partnerships to identify their housing problems and to develop a strategy for solving the problems. The maximum Community Planning Grant award amount is \$15,000.

Direct Loan Program. Administered by the USDA, the Section 515 Direct Loan Program provides loans to developers, both for-profit and not-for-profit, to enable them to construct or rehabilitate rental housing in rural areas for very-low-income, low-income, and moderate-income tenants. (This program also provides rental assistance to very-low-income and low-income tenants.) Loans of as much as 97 percent of development costs are provided for a 30-year period but amortized over a 50-year period. The interest credit decreases the interest rate to one percent.

Guaranteed Loan Program. The USDA's Section 538 Guaranteed Loan Program guarantees loans made by private lenders to developers, both for-profit and not-for-profit, to enable them to construct or rehabilitate rental housing in rural areas. Units must be reserved for tenants with incomes less than or equal to 115 percent of the area median income. Rental charges cannot exceed 30 percent of 115 percent of the area median income. The maximum loan under this program is 90 percent of the development costs. USDA guarantees 90 percent of the loan amount.

Low Income Housing Tax Credit. The Low Income Housing Tax Credit (LIHTC) encourages the construction and rehabilitation of rental housing for lower-income households by offering credits on federal taxes for 10 years. Annually, the U.S. Department of Treasury allocates tax credits to each state. The tax credits are offered to owners of rental housing developments who are willing to set aside a minimum of the development's units for households earning 60 percent or less of gross median income. The owner of the development will form limited partnerships with investors who are willing to provide funding for the development in return for the economic benefit of the tax credit. The amount of the tax credit is determined at the time the tax credit is allocated and is based on several factors including the depreciable development costs, the type of

development (new construction, rehabilitation or acquisition), percentage of housing units designated for use by persons with low income. Maine Housing Investment Fund purchases Low Income Housing Tax Credits to provide equity for affordable housing projects; the tax credits are in turn sold to investors.

Community Reinvestment Act. The Community Reinvestment Act (CRA) was enacted in 1977 to encourage banks and thrifts to help meet the needs all segments of their communities, including low- and moderate-income neighborhoods. The Office of the Comptroller of the Currency, Board of Governors of the Federal Reserve System, Federal Deposit Insurance Corporation, and Office of Thrift Supervision share responsibility for assessing whether banks and thrifts serve the their communities. Considered in the assessment is whether mortgages are made to low income households and loans are made to small businesses. When a bank or thrift seeks approval of a merger, acquisition, and branch opening, its record under the CRA is considered.

Community Development Financial Institution Fund. The Community Development Financial Institution Fund provides funding to Community Development Financial Institutions (CDFIs) are specialized financial institutions that work in market niches that have not been adequately served by traditional financial institutions. CDFIs can provide a wide range of financial products and services, including mortgage financing for first-time home-buyers, financing for needed community facilities, commercial loans and investments to start or expand small businesses, loans to rehabilitate rental housing, and financial services needed by low-income households and local businesses. CDFIs can also provide technical assistance to small businesses and credit counseling to consumers. CDFIs include community development banks, credit unions, loan funds, venture capital funds, and microenterprise loan funds, among others. Coastal Enterprises, Inc. and Community Concepts are both CDFIs in Maine.

New Lease Program. MSHA's New Lease Program provides low-interest-rate loans to private and non-profit developers to enable them to finance and rehabilitate buildings with four to 19 units. MSHA will only finance 35 units in a community each year. The program requires that developers rent 40 percent of the units to tenants with incomes at or below 40 percent of the area median income and one of those units to a tenant with an income at or below 30 percent of the area median income. In addition, it requires that developers rent 30 percent of the units to tenants with incomes at or below 60 percent of the area median income.

Rental Loan Program. MSHA's Rental Loan Program provides low-interest-rate loans to private and non-profit developers to enable them to finance rehabilitation, acquisition and rehabilitation, or construction of large-scale, multi-family housing projects. MSHA's priority is to preserve low-income housing that might be lost due to the end of a federal rental assistance contract, physical deterioration, or the decision by the landlord not to participate in a federal program. The Rental Loan Program combines bond proceeds with subsidy funds and federal Low-Income Housing Tax Credits (discussed above) for the acquisition and rehabilitation or construction of housing projects with a minimum of 10 units. The program requires that 20 to 40 percent of the units be affordable to tenants with very low incomes.

Housing Development Programs for People with Disabilities

There are a number of programs aimed at developing affordable housing for persons with disabilities. These housing programs include:

- Section 811;
- Section 202;
- Supportive Housing Program for the Homeless;
- Housing Opportunities for Persons with AIDS;
- MSHA's Supportive Housing Program; and
- BEAS' Congregate Housing Demonstration Program.

There are several federal supportive housing programs, as well as state-initiated supportive housing efforts.

Section 811, Supportive Housing for People with Disabilities. Section 811, of the National Affordable Housing Act of 1990, funds supportive housing for persons with disabilities. Under Section 811, supportive housing includes transitional housing, group homes, emergency shelters, single room occupancy residences, and supported or independent apartments. Section 811 funding can be used to fund group homes with 8 or fewer residents or supportive housing for up to 24 residents. Populations with special needs include individuals with mental retardation, victims of domestic violence, frail elders, foster children, individuals with physical disabilities or AIDS, ex-offenders, and individuals with substance abuse problems.

Under Section 811, interest-free capital is advanced to finance the development of supportive housing. Residents pay 30 percent of their income in rent while Section 811 pays the difference between operating costs and the rent received from the tenant.

Section 202, Supportive Housing for the Elderly. Section 202 of the Housing Act of 1959 is comparable to Section 811. Section 202 funding can be used to fund efficiencies and one-bedroom units with supportive services. Supportive services include cleaning, cooking, and transportation. Unlike Section 811 projects, funding for services is not a priority. Services are only funded after monthly debt and operations costs are paid.

Supportive Housing for the Homeless. HUD has another supportive housing program designed to help homeless people live as independently as possible by encouraging the development of housing and related supportive services for people moving from homelessness to independent living. Under the McKinney-Vento Homeless Assistance Act, this program provides funds to states, local governments, public housing authorities, and non-profit organizations, and it supports five types of programs: transitional housing to help homeless people move to permanent housing; permanent housing for homeless people with disabilities; Safe Havens, which provide 24-hour supportive housing for hard-to-reach homeless people with severe mental illness; supportive services for homeless people; and other types of supportive housing for homeless people. Supportive services include childcare, employment assistance, outpatient health services, case management, assistance in locating permanent housing, nutritional counseling, security arrangements, and other assistance.

Housing Opportunities for People with AIDS. Housing Opportunities for Persons with AIDS (“HOPWA”) is a HUD program designed to provide housing assistance and supportive services for low-income people with HIV/AIDS and their families. Funds may be used for housing information services; resource identification; project-based or tenant-based rental assistance; short-term rent, mortgage, or utility payments to prevent homelessness; housing and development operations; and supportive services.

MSHA’s Supportive Housing Program. MSHA’s Supportive Housing Program provides low-interest-rate loans and subsidies to tax-exempt, non-profit corporations to enable them to finance acquisition and rehabilitation or construction of supportive housing for people who are homeless and people with special needs. Supportive housing includes transitional housing, group homes, emergency shelters, single room occupancy residences, supported or independent apartments, or other group living environments with residential programs. People with special needs include the frail elderly, people with mental illness, special needs children, individuals with physical disabilities, people with AIDS, people with mental disabilities, and victims of domestic violence.

Rental Assistance

Rental assistance is another way of increasing the affordability of housing. Some rental assistance comes in the form of a voucher, which a consumer can use to pay rent on any reasonably priced rental with a landlord willing to accept it. Other rental assistance is associated with particular housing developments. This section reviews the primary sources of rental assistance, noting some of the other programs that provide rental assistance.

Section 8. Section 8 is the primary rental assistance program, offered generally to low-income people. Vouchers are distributed by HUD to PHAs (including MSHA), which in turn distribute vouchers to eligible individuals. The PHA applies for the vouchers and can apply for vouchers available to the general low-income population and for vouchers available to people with disabilities. The Mainstream Program is designed to enable very-low-income people with disabilities to rent the affordable, private housing of their choice. Under this initiative, PHAs and non-profit disability organizations can apply for vouchers designated for people with disabilities. The Designated Housing Plans Program provides PHAs with another opportunity to apply for vouchers targeted for people with disabilities who would have been housed but for the designation of projects as restricted to elderly tenants. This program also provides funding to PHAs that maintain “mixed” projects but can demonstrate a need for alternative resources for people with disabilities.

A limited number of vouchers for Section 8 tenant-based rental assistance are available to families with income at or below 50 percent of the median income for the county or metropolitan area where they live. TABLE 27 lists the income limits by county for the year 2002.

Table 27. Gross Income Limits by County, Effective 1/31/02¹⁴¹

| County | 1 person | 2 person | 3 person | 4 person | 5 person | 6 person |
|------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Androscoggin | \$ 24,000 | \$ 27,450 | \$ 30,900 | \$ 34,300 | \$ 37,050 | \$ 39,800 |
| Kennebec | \$ 24,150 | \$ 27,600 | \$ 31,050 | \$ 34,500 | \$ 37,250 | \$ 40,000 |
| Lincoln | \$ 22,700 | \$ 25,900 | \$ 29,150 | \$ 32,400 | \$ 35,000 | \$ 37,600 |
| Penobscot | \$ 22,700 | \$ 25,900 | \$ 29,150 | \$ 32,400 | \$ 35,000 | \$ 37,600 |
| Sagadahoc | \$ 25,100 | \$ 28,650 | \$ 32,250 | \$ 35,850 | \$ 38,700 | \$ 41,550 |
| *Cumberland/York | \$ 27,450 | \$ 31,350 | \$ 35,300 | \$ 39,200 | \$ 42,350 | \$ 45,450 |
| *All Others | \$ 21,050 | \$ 24,050 | \$ 27,050 | \$ 30,100 | \$ 32,500 | \$ 42,800 |

**=1yr out of date; figures to be updated*

The amount of the voucher is based on the fair market rent (FMR) for the area. HUD establishes FMR based on local rent levels. For a one-bedroom apartment, the FMR is \$447 per month in Bangor, \$407 per month in Lewiston-Auburn, and \$621 per month in Portland.¹⁴² The PHA establishes a Section 8 voucher "payment standard" which is between 90 and 110 percent of the Fair Market Rent. Participants pay between 30 to 40% of adjusted income toward rent and utilities. Assistance is continued until the rent equals the household's share of the rent, or 30% of income.

As an example, the Section 8 voucher might be calculated this way:

| | |
|---|-------|
| Fair Market Rent in Town X | \$400 |
| Payment standard (calculated at 110% FMR) | \$440 |
| Income (\$545 SSI + \$10 state supp.) | \$555 |
| Counted income (30% of income) | \$167 |
| Subsidy (payment standard – counted income) | \$273 |
| Actual rent | \$450 |
| Tenant pays | \$177 |

With a voucher in hand, it is up to the eligible individual to locate housing that meets required standards and with a landlord willing to accept a voucher. The housing must meet HUD's housing quality standards and is subject to health and safety inspections by housing authorities. The rent must be reasonable relative to comparable housing units. A housing authority pays the appropriate rental subsidy directly to the landlord, and the tenant is responsible for paying the remainder of the monthly rent. Tenants must pay their own security deposits unless they can secure assistance from another program.

¹⁴¹ FY 2002 Section 8 income limits, excerpted from http://www.huduser.org/datasets/il/fmr02/prts801_02.doc

¹⁴² Maine State Housing Authority, *Fair Market Rents for Existing Housing, Effective October 1, 2001*.

Project-based rental assistance means that the subsidy is tied to a housing unit, rather than the tenant. A participant can use the subsidy while residing in that unit. A PHA can allocate up to 20% of its vouchers to project-based subsidies. The PHA enters into an agreement with an owner to apply voucher assistance to specific units, if the owner agrees to rehabilitate or build the units. When a subsidized tenant lives in one of the units, the PHA pays the owner the difference between 30 percent of that person's income and the gross rent for the unit. A person leaving a unit subsidized by a project-based voucher cannot take the voucher, and must reapply for another voucher.

As of 1999, Maine had 8,671 project-based Section 8 units. Most of these units are located in Cumberland, York and Androscoggin counties.¹⁴³

Bridging Rental Assistance Program (BRAP). BRAP is a state-funded program, available through BDS regional offices or through one of several community providers under contract with BDS. BRAP is a "shallow" rental subsidy designed to assist people who are on a waiting list for a Section 8 housing subsidy. BRAP pays the difference between fair market rent, including utilities, and 51% of a tenant's income for up to two years. All BRAP units must meet or exceed HUD's housing quality standards so that the tenant will be able to stay in the same apartment when the Section 8 voucher becomes available.

Eligibility is limited to persons with psychiatric disabilities who are receiving Supplemental Security Income or Social Security Disability Insurance benefits. Priorities for receiving BRAP funding include: individuals who are leaving or have been discharged within the last six months from state-operated or private psychiatric hospitals; people who are homeless; persons moving from community residential programs funded by BDS to more independent living arrangements; and people who are living in substandard housing as defined by HUD.

Shelter Plus Care. Shelter Plus Care (S+C) is part of the McKinney-Vento Homeless Assistance Act of 1987. Shelter Plus Care provides rental assistance. BDS administers multiple Shelter Plus Care one and five-year grants awarded by HUD. BDS has used the \$7.5 million in grant funds to provide rental assistance and support services to adults with serious mental illness and other disabilities. At the end of fiscal year 2000, the grant funds provided subsidies for 1200 people since its inception. For the current year, 420 housing units are funded, but this number will likely remain the same in the coming year. Grant renewals are now funded on an annual basis.

Other Sources of Rental Assistance. As described above, programs funding the development of rental housing also often provide rental assistance as well. These programs include: HOME Investment Partnership Program transitional rental assistance; Housing Opportunities for People with AIDS (HOPWA); Section 202 Supportive Housing for the Elderly; and Section 811, Supportive Housing for the People with Disabilities.

¹⁴³ *The State of Maine's Housing 1999*, Maine State Housing Authority.

Homeownership and Home Modification

Several programs promote homeownership and home repairs and home modification. Described here are:

- Section 8 voucher home ownership program;
- Individual Development Account;
- MSHA home repairs programs
- Rehabilitation Mortgage Insurance;
- Property Improvement Loan Insurance;
- Independent Living Services;
- the MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program;
- Home modification funded through MaineCare waiver services;
- The HOME Retro Program; and
- Community Development Block Grant.

Some of these programs are available through private lenders. Others are available through non-profit organizations, public housing authorities or state government. Some of the programs are for people with low-incomes generally. Others are targeted at people with disabilities. The programs offer a range of mechanisms, including loan insurance, loans, grants, or other incentives or tools to promote homeownership. The programs might pay for home modification or repair, or might be designed to increase homeownership.

Section 8 Home Ownership Program. Effective October 2000, the Section 8 homeownership program permits current tenants to convert vouchers from rental supplements to mortgage supplements. For communities with participating PHAs, applicants can choose between home ownership and home rental. Under this program, one or more adult family members must be employed at least 30 hours per week, and the family must have an annual income equal to 2,000 hours of annual full-time work at the federal minimum wage. However, the employment requirement does not apply to a family with a member who is elderly or has a disability; welfare assistance for families with an elderly member or a member with a disability must be counted toward the minimum income requirement.

The Section 8 homeownership program offers a new opportunity for low-income people, including people with disabilities. However, this program requires both public housing authorities and lending institutions to buy into the program. Some are concerned that lenders are reluctant to participate in the Homeownership program because, while mortgage terms might extend for 30 years, Congress' confirmed commitment to the Homeownership program only extends from one budget to the next.

Individual Development Accounts. The Finance Authority of Maine oversees the Family Development Account Program, which allows low income individuals to develop tax exempt savings. The savings can be used for several different purposes, including the purchase or repair of the person's home. The program is limited to persons whose family income is below 200% of the poverty line. The accounts are administered by a nonprofit community development organization. The community development organization may make matching contributions up to \$2000 per year, until the account exceeds \$10,000. The funds are tax exempt up to \$25,000.

Homeownership Loans. Although not currently funded, Maine's Department of Behavioral and Developmental Services (BDS) has operated a homeownership loan program for people with disabilities called Home Assistance Venture II (HAVII) with the assistance of the Federal Home Loan Bank of Boston, MSHA, the USDA, and private lending institutions. HAVII helps with down payments and closing costs or to reduce the amount of an existing mortgage. HAVII is administered by Coastal Enterprises, Inc.

Pilot Home Rehabilitation Program. As a pilot in four counties (Cumberland, Knox, Hancock and Washington), the Home Rehabilitation Program provides loans to low income homeowners for renovations and replacement of failing building parts. Loans are available at 1 percent interest with a maximum loan amount of \$15,000. Loans are distributed through Community Action Programs.

Rehabilitation Mortgage Insurance. Funded through HUD, the rehabilitation mortgage insurance program insures loans made by private lenders to cover both the acquisition or refinancing and rehabilitation of a home. Insured loans can be used to finance minor rehabilitation or major reconstruction, including enhancing accessibility for persons with disabilities. By providing mortgage insurance, the lender has more incentive to loan to persons who otherwise typically do not qualify for loans at affordable terms, such as persons with low incomes.

Property Improvement Loan Insurance. Funded through HUD, the property improvement loan insurance program also insures home improvement loans made by private lenders. This program permits homeowners or tenants to make permanent property improvements. A tenant is eligible for the program only if his or her lease extends six months beyond the date when that final loan payment is due.

Independent Living Services. Independent living services, provided through the Bureau of Rehabilitation Services, BDS, and BEAS all pay for home modification services. BRS administers two independent living programs, one general program offered through Alpha One and a second for person who are blind or visually impaired, offered through the Iris Network. The program services include home modifications, ramp installations, adaptive equipment and assistive technology devices, etc. The federally funded program allows total costs of up to \$5,000 per participant (over a lifetime), with exceptions allowed in certain circumstances. Please see INDEPENDENT LIVING SERVICES for more discussion of the services offered through BRS, BDS, and BEAS.

MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program. The MPower Adaptive Equipment Loan Program provides loans for adaptive equipment to any Maine citizen or business can demonstrate that the loan will assist a person with disability to become more independent. Applications for individual loans are made through AlphaOne. Applications for businesses are made through the Finance Authority of Maine. The MPower Adaptive Equipment Loan Program Fund Board reviews applications at its monthly meeting.

HOME Retro Program. The HOME Retro program provides up to \$15,000 in a grant to make home modifications for a resident with a disability. The grantee must own their residence and

have a person with a disability living in the home; meet financial eligibility criteria; and use at least 75% of the grant funds for accessibility rehabilitation. The property must also meet certain minimum standards. Funds can be used for widening doorways, building a ramp, remodeling a kitchen, bathroom or bedroom or other modifications. Funding for the HOME Retro Program is provided through a collaborative agreement between Alpha One and MSHA.

Community Development Block Grant. Block grant funds can be used to fund rehabilitation of single family homes or to assist low income homebuyers with down payments, subsidized interest, etc.

Fair Housing Laws

In response to discriminatory practices and the need for housing that accommodates the needs of persons with disabilities, the federal and state government have enacted laws governing civil rights, accommodations and construction, including:

- the Fair Housing Act;
- Section 504 of the Rehabilitation Act;
- Architectural Barriers Act;
- Americans with Disabilities Act;
- Maine Human Rights Act; and
- State public housing construction laws.

Fair Housing Act

Amended in 1988 to include persons with disabilities among those protected, the Fair Housing Act (FHA) prohibits discrimination in the sale, rental and financing of dwellings. The FHA contains design and construction accessibility provisions for certain new multifamily dwellings developed for first occupancy on or after March 13, 1991. The FHA does not cover owner-occupied buildings with four or fewer units. It also does not cover units or buildings rented or sold by an owner who does not use advertising, a real estate agent, or a broker.

Complaints filed with HUD are investigated by the Office of Fair Housing and Equal Opportunity (FHEO). If the complaint is not successfully resolved then FHEO determines whether to enforce the complaint on behalf of the individual that filed it. HUD can also rely on state and local agencies to enforce the FHA.

Pursuant to the Fair Housing Act, the Fair Housing Accessibility Guidelines set forth standards for accessible entrances on an accessible route; accessible public and common use areas; usable doors; accessible routes into and within the unit; switches, outlets, and environmental controls; kitchens; bathrooms; and reinforced walls. These standards apply to all units in buildings with elevators and all ground floor units. As one example, there must be one common entrance to a multi-family residence that is accessible. That entrance must be typically used by all residents and cannot be a service entrance or loading dock. It must be on a route that a person using a wheelchair can travel. As another example, wall outlets must be located a minimum of 15 inches above the finished floor and light switches between 48 and 54 inches above the finished floor.

If requested, landlords must make reasonable accommodations for tenants with disabilities. For example, a landlord must reserve an accessible parking space for a tenant with mobility impairment or make an exception to a policy against pets to permit service dogs. Likewise, if requested, landlords must allow tenants with disabilities to make reasonable accommodations in their own units at their own expense. For example, a landlord must allow a tenant with a mobility impairment to install grab bars in the bathroom or lower light switches.

Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against persons with disabilities in any program or activity receiving federal financial assistance. Thus, even private landlords who accept federal subsidies are covered by the Act. HUD is required to investigate discrimination in HUD-provided programs and activities. Individuals file complaints with HUD's Office of Fair Housing and Equal Opportunity (FHEO).

Architectural Barriers Act

The Architectural Barriers Act (ABA) requires buildings and facilities that are constructed by or on behalf of, or leased by the United States, or buildings financed, in whole or in part, by a grant or loan made by the United States to be accessible to persons with mobility impairments. The Architectural and Transportation Barriers Board (ATBCB) has coordination authority for the ABA.

Americans with Disabilities Act

Title II of the Americans with Disabilities Act of 1990 prohibits state and local governments from excluding people with disabilities from public housing programs, whether or not federal funds are involved. HUD's Office of Fair Housing and Equal Opportunity enforces the ADA for housing-related complaints.

Maine Human Rights Act

The Maine Human Rights Act, 5 M.R.S.A. § 4582-A, prohibits unlawful housing discrimination on the basis of disability. Pursuant to that Act, landlords must permit tenants with physical disabilities to make reasonable modifications of the premises at their own expense. Likewise, landlords must make reasonable accommodations in rules, policies, practices, or services to enable tenants with disabilities to use and enjoy the premises.

State Public Housing Construction Laws

Under the public safety statutes governing the construction of public buildings, newly constructed housing containing 20 or more units, and constructed with federal or state funds must meet certain accessibility standards for persons with physical disabilities.¹⁴⁴

¹⁴⁴ 25 M.R.S.A. § 2701 et. seq.

Transportation

While many people take the availability of transportation and driving their own car for granted, for many persons with disabilities the accessibility and availability of transportation is a major barrier to fully participating in community living. The absence of regular, reliable transportation can interfere with the ability to get and keep a job, access to medical appointments and other essential services, shopping for groceries and other essential goods, participation in community meetings and events, attending concerts, plays, religious services, or recreational and sporting events, visiting relatives, friends, or being otherwise integrated and involved in the fabric of community life.

This section describes the transportation services available to persons with disabilities and some of the issues and barriers to fully meeting the need for accessible and available transportation. In particular, this section includes:

- the role of state agencies;
- initiatives to address transportation problems;
- transportation options; and
- other steps and measures.

Organization of Transportation Services

Multiple state agencies play a role in managing or funding transportation services, including the:

- Department of Transportation (DOT);
- Department of Human Services (DHS) (including Bureau of Medical Services; Bureau of Elder and Adult Services; and Bureau of Child and Family Services);
- Department of Behavioral and Developmental Services (BDS);
- Department of Education; and
- Department of Labor.

Maine Department of Transportation (MDOT)

Maine organizes public transportation services by regions that mostly follow county boundaries (see TABLE 28 and MAP 1 below). The MDOT distributes federal and state public transit funds to each region. Each region has a Regional Transportation Advisory Committee (RTAC) that offers advice to MDOT on a full range of transportation issues including highways, airports, ferry service, rail, bus, and transportation for persons with disabilities. Each RTAC has between 16 and 21 members, each appointed by the Commissioner of Transportation to a three-year term. The membership of each RTAC is meant to represent a broad collection of interests, including the elderly and persons with disabilities.

While most regions have multiple public transportation providers, MDOT contracts in each region with a lead regional public transportation agency for primary responsibility for general public transportation. By arrangement with MDOT, other Departments, including DHS and BDS, often use the same transportation providers to provide or arrange for non-emergency

medical transportation for MaineCare members, and for other state-funded human services. The rationale for regional coordination across state agencies is to make efficient use of vehicle and driver resources and to take advantage of the federal and state capital equipment funds that MDOT distributes to the lead transportation providers.

Map 1: Maine Transportation Regions



Source: Maine Department of Transportation

Table 28. Maine Transportation Regions

| Region | Counties | Primary Provider Agency |
|--------|---|--|
| 1 | Aroostook | Aroostook Regional Transportation System, Inc. (ARTS) |
| 2 | Hancock, Washington | Washington-Hancock Community Agency (WHCA) |
| 3 | Penobscot, Piscataquis | Penquis Community Action Program |
| 4 | Kennebec, Somerset | Kennebec Valley Community Action Program |
| 5 | Knox, Lincoln, Sagadahoc, Waldo | Coastal Trans, Inc. (CTI) (The Waldo County Committee for Social Action is responsible for Waldo County under joint agreement with Coastal Trans.) |
| 6 | Cumberland, 9 towns in Oxford | Regional Transportation Program (RTP) |
| 7 | Androscoggin, Franklin and the rest of Oxford | Western Maine Transportation |
| 8 | York | York County Community Action Corp. |

Each regional entity is responsible for:

- providing buses, small buses, and vans;
- planning and redesigning a mix of fixed-schedule and demand-responsive flexible routes;
- hiring and training paid drivers;
- recruiting and training volunteers to use their own vehicles to offer rides in return for a mileage reimbursement under programs funded by other departments; and
- taking reservations and scheduling trips.

In addition to the regional transportation providers, MDOT also uses federal and state funds to subsidize vehicle purchase costs for several fixed schedule-fixed route providers listed below in TABLE 29.

Table 29. Maine Fixed Schedule – Fixed Route Transportation Providers

| Region | Provider(s) |
|--------|---|
| 2 | Downeast Transportation and West's Transportation |
| 3 | The Bus (greater Bangor area) |
| 5 | Bath City Bus |
| 6 | METRO (Portland), South Portland Bus Service, Casco Bay Island Transit District (ferry service) |
| 8 | The ShuttleBus (Biddeford, Saco, and Old Orchard Beach) |

The Role of Federal Funds. In all, there are about 70 federal programs that provide transportation funds benefiting persons with disabilities in whole or in part. Other than the federal share of Medicaid reimbursement, the principle source of federal funding for transportation services for persons with disabilities is the U.S. Department of Transportation's Federal Transit Administration (FTA) Section 5310 Elderly and Disabled Transportation Assistance Program. In FY2000, Maine received \$483,500 in Section 5310 funding, based principally on the number of elderly and persons with disabilities counted in the 1990 census.

Section 5310 funds are generally restricted to covering the 80% federal share of capital costs for vehicles, computers, and office equipment for non-profit and for-profit transportation agencies. In most cases, Section 5310 funds cannot be used to subsidize any operating costs, including driver salaries, training, or scheduling and planning operations. In FY2000, Maine used its full Section 5310 allocation for the purchase of 5 small buses and 6 modified vans distributed across 9 different transportation providers.

However, a few states, notably Vermont, have taken advantage of two special provisions of the Section 5310 federal rules to greatly increase federal dollars for Elderly and Disabled Transportation Assistance:

- Under Chapter I, Section 5b of the rules, states can transfer flexible funds from the much larger federal Surface Transportation Program (funds normally used for road paving) into the 5310 Program; and
- Chapter II, Section 7m allows states to use Section 5310 money to subsidize local transit provider operating costs, if the state purchases transportation services from those providers under contract or lease.¹⁴⁵

In addition, Vermont's Department of Transportation has worked closely with their congressional delegation to obtain earmark funds (special appropriations members of Congress obtain for their own states) to pay for some of the bus and van purchases normally paid for by Section 5310. Although Vermont's original FY2000 Section 5310 allocations was about half of Maine's (\$266,000 compared to \$483,500), Vermont ended up with \$675,000 to purchase 16 vans and \$2.2 million for Section 5310-related operating costs.^{146*}

While DOT officials have an interest in exploring these options, Maine's situation is very different. Most of the flexible funds that Vermont shifts to Section 5310 are air quality improvement funds. While Vermont has no officially designated air quality problem areas, Maine has several and cannot shift federal transportation money away from air quality improvement projects.¹⁴⁷ Maine would also have more difficulty shifting Surface Transportation road paving funds into the Elderly and Disabled Transportation Program since federal highway

¹⁴⁵ Federal Transit Administration Circular 9070.1E, U.S. Department of Transportation, (Washington), http://www.fta.dot.gov/library/policy/9070_1E/toc.html.

¹⁴⁶ Telephone interview with Patricia Crocker, Executive Director of the Vermont Public Transportation Association, April 2001.

* Even with Vermont's greater access to federal funds, there are still many locations that get served by bus or van only once or twice each week.

¹⁴⁷ Telephone interview with Barbara Donovan, DOT, May 2001.

dollars are already stretched thin. Because the population is so spread out, Maine has 35 feet of state highway to maintain per state resident, five times as much state highway per resident as the rest of New England. This means the cost per resident to maintain state highways is much higher than in the other New England states. At the same time, Maine receives less than one-fifth in federal highway funds per mile of road than the New England regional average.¹⁴⁸ Both factors make it more difficult for Maine to afford to switch monies away from other surface transportation needs and into Section 5310.

Some of the FTA's other relevant programs include the Section 5309 Capital Program and Section 5311 Rural Transportation Program. Neither program is specifically targeted to persons with disabilities, but in Maine, many of the same transportation providers receive these funds. Maine uses its Section 5309 money to help transit agencies and companies purchase buses, vans, and, on occasion, ferries. Maine DOT uses 5311 Rural Transportation funds to subsidize operating costs in rural areas for many of the same providers who receive Section 5310 monies. Other programs that were authorized to provide monies for transportation in the FY 2000 federal budget included:¹⁴⁹

Department of Health and Human Services (DHS)

Administration on Aging

- Grants for State & Community Programs on Aging (Title III)
- Grants for Native Americans (Title VI)

Administration for Children and Families

- Child Care and Development Block Grant
- Developmental Disabilities Basic Support and Advocacy Grants
- Developmental Disabilities Projects of National Significance
- Head Start
- Community Services Block Grant (CSBG)
- Social Services Block Grant (SSBG)
- Temporary Assistance to Needy Families (TANF)
- Refugee and Entrant Assistance Programs

Centers for Medicare and Medicaid Services (CMS, formerly HCFA)

- Medicaid

Health Resources and Services Administration

- Community and Migrant Health Centers

¹⁴⁸ Maine Economic Development Foundation, *Maine's Transportation System: Status and Trends Indicators of Economic Growth and Quality of Life*, October 1999, p. 2.

¹⁴⁹ "Resource Guide, 2000: Federal Funding Sources," Community Transportation Association, http://www.ctaa.org/ct/resource/funding_2000.shtml.

Substance Abuse and Mental Health Services Administration

- Community Mental Health Services Block Grant
- Substance Abuse Prevention and Treatment Block Grant¹⁵⁰

Department of Housing and Urban Development (DHHS)

Office of Housing

- Supportive Housing for Persons with Disabilities
- Service Coordinators for the Elderly and Disabled in Public Housing

Office of Community Planning and Development

- Community Development Block Grants
- Supportive Housing Program
- Housing Opportunities for Persons with AIDS
- Urban Empowerment Zones/Enterprise Communities

Office of Public and Indian Housing

- Public Housing Drug Elimination Program
- Indian Community Development Block Grant Program
- Revitalization of Severely Distressed Public Housing
- Title VI Native American Housing Loan Guarantee Fund
- Resident Opportunities and Self Sufficiency Program

Department Of Education

Office of Postsecondary Education

- Federal TRIO Programs

Office of Special Education and Rehabilitative Services

- Vocational Rehabilitation Grants
- Centers for Independent Living
- Independent Living Services for Older Individuals Who are Blind
- Vocational Rehabilitation Demonstration and Training Programs

Department of Agriculture

Rural Community Advancement Program

- Rural Development Loan Fund
- Rural Economic Development Loans

¹⁵⁰ "Federal Resources for Specialized Transportation Services," Federal Transit Administration, U.S. Dept. of Transportation, <http://www.fta.gov/library/policy/guide/ch3.html>.

Department Of Commerce

Economic Development Administration

- Economic Development Grants

Department of Defense

Office of Economic Adjustment

- Base Realignment and Closure

Department of the Interior

Bureau of Indian Affairs

- Indian Financial Assistance and Social Services Programs
- Indian Credit Program

Department Of Justice

Office of Justice Programs

- Crime Victim Assistance
- Weed and Seed

Department Of Labor

Employment and Training Administration

- Unemployment Insurance
- Senior Community Service Employment Program
- Workforce Investment Pilot and Demonstration Programs
- Workforce Investment Act Programs
- Native American Employment and Training Programs

Veterans' Employment and Training Service

- Homeless Veterans' Reintegration Project

Department Of Veterans Affairs

Veterans Health Administration

- Veterans Medical Care Benefits
- Veterans Nursing Home Care
- VA Homeless Providers Grant and Per Diem Program

Environmental Protection Agency

- Environmental Protection State and Tribal Assistance Grants

Federal Emergency Management Agency

Public Assistance Grants

- 83.551 Project Impact Grants

Department of Human Services (DHS)

Within the Department of Human Services, the Bureau of Medical Services and the Bureau of Elder and Adult Services play a role in providing transportation services to persons with disabilities.

Bureau of Medical Services. The Bureau of Medical Services administers the MaineCare program (Maine's Medicaid program). MaineCare pays for non-emergency medical transportation for covered by MaineCare. Non-emergency medical transportation is Maine's largest source of funding for transportation for persons with disabilities. By rough estimate, MaineCare pays for upwards of three-quarters of all state-reimbursed medical and social services consumer trips in Maine. These include trips taken by transit bus, van, volunteer driver or taxi, and trips where a MaineCare member, family member or friend is reimbursed for gasoline at 15¢ per mile for using their own car.

Due to several federal court rulings, all states are required to assure or provide transportation to covered medical services for any Medicaid beneficiary who has no other method of travel. In fiscal year 2000, about 24,500, or 14% of *all* MaineCare members used non-emergency medical transportation at a cost of nearly \$14 million dollars or a little over 1% of the total Maine MaineCare budget.¹⁵¹ In FY1997, the percentage of MaineCare members served by non-emergency Medicaid transportation was nearly 1½ times the national average.¹⁵² The annual cost averaged out to \$568 for each transportation user in the Maine MaineCare system.

MaineCare will pay for transportation only when the transportation is for a MaineCare covered service and the member has no other transportation available from self, family, neighbors, or voluntary organizations. Trips must be arranged through a designated regional public transportation agency. MaineCare will only pay for the least expensive, appropriate method to travel the shortest distance to the nearest appropriate provider of a covered service. The regional transportation provider agency is responsible for determining the least expensive appropriate method. In most cases, this means reimbursing the MaineCare member or family member for using their own car in a rural area, or purchasing a bus ticket or bus travel voucher in a city. However, in other cases, the most appropriate method might be a lift-equipped van, a volunteer driver, or an airplane ticket to access a specialized service out-of-state. All non-emergency trips

¹⁵¹ "Annual Report to the State Legislature: Medicaid in Maine SFY 2000," Maine Bureau of Medical Services, (Augusta, ME: 2001).

¹⁵² "Managing Medicaid Transportation: A Manual Examining Innovative Service Delivery Models," Community Transportation Association of America, The National Transit Resource Center, (Washington, DC: December 1997).

must be arranged in advance with some regional providers requiring a three or even five-day advance reservation.

MaineCare's only exception to the MaineCare covered service rule is the public transit voucher system. If a MaineCare member uses a fixed-schedule public transit bus for three-or-more MaineCare covered service trips per month, they can receive a voucher for a monthly bus pass allowing them to use the bus for any purpose, including shopping and recreation. The MaineCare bus pass program is available in Portland and Bangor. The regional transportation agency confirms the monthly number of MaineCare trips and arranges for the bus pass.

Bureau of Elder and Adult Services (BEAS). Federal Older Americans Act funds administered by BEAS are allocated to the state's five area agencies on aging, who develop plans based on regional needs assessment that identify service priorities and how the funds will be spent. One of the two major programs under the Act covers a broad range of social services, including transportation (the other program is for nutritional services). In FY 2001, the area agencies allocated \$74,500 to support transportation services for people 60 years of age and older. They have also allocated \$111,000 in BEASE state social services funds to support this effort. Most of this money is spent on medical transportation for persons not covered by Medicaid, and to bring older persons to senior meals sites.¹⁵³ While some of the persons served by these funds have physical disabilities or cognitive impairments, it is impossible to determine what portion of the BEAS' transportation funds are used to pay for disability-related travel.

Department of Behavioral and Developmental Services (BDS)

BDS provides some support for transportation services for both adults with mental retardation and adults with mental illness.

Adults with Mental Retardation. For adults with mental retardation or developmental disabilities (MR/DD), transportation funds are devoted to travel to work, and travel to attend day programs, with some funds used for travel to community, recreational, or social activities. Until 1994, BDS relied heavily on the regional transportation service providers throughout the state. Today, BDS' methods to arrange and pay for transportation vary tremendously across different programs and geographic regions. In some areas, BDS still relies on the designated regional public transit agencies. In others, the BDS arranges for Medicaid funds to reimburse family, friends, or volunteers, or will reimburse a job coach to take the consumer to work, or will leave transportation responsibilities to a day program, or group home and include the costs in the overall per diem rate.

While some designated regional transit providers are able to offer the services required by BDS consumers, others cannot match their resources to the requirements of BDS consumer work schedules. Many transit schedules are structured around the expectation that workers will leave outlying areas to go to work in the early morning and leave their jobs between 4 o'clock and 5 o'clock to return. Many BDS consumers work at part-time jobs or non-traditional work hours, for example, a 6 p.m.-to-midnight shift.

¹⁵³ Telephone interview with John Baillargeon, Maine Bureau of Elder and Adult Services, May 2001.

Providing transportation through day program and group home contracts can offer consumers greater travel flexibility since travel is not tied to fixed van schedules or 3-to-5-day advance reservation requirements.

Another impediment to BDS' reliance on regional transit agencies is cost. Reimbursement to family drivers, volunteer drivers, day programs, and group home owners are often a much less expensive alternative. BDS estimates that average transit agency charges exceed one dollar per mile. In rural areas where consumers may live far from a day program, transit agency charges exceed the cost of the day program itself.¹⁵⁴

On the other side of the coin, when BDS ended its reliance on some regional transportation providers in 1994, those providers found their programs disrupted and the level of service to other persons with disabilities seriously affected. For example, the Western Maine Transportation Service, the regional provider for Androscoggin, Franklin, and most of Oxford counties could no longer afford to keep all their buses on the road, and towns like Farmington, Rumford, and South Paris had their bus service cut in half.¹⁵⁵

BDS' decisions illustrate a tension between competing goals — maximizing efficient vehicle use and the efficient use of scarce transportation dollars by coordinating all types of human service transportation through a single regional transport agency, versus maintaining a needed level of travel flexibility for a department or bureau's own consumers by purchasing dedicated vans for individual human service providers.

Because so many of BDS' transportation services are incorporated into general provider day rates for all services, it is impossible to determine how much money BDS spends on transportation or how many trips are provided.

Adults with Mental Illness. Case managers make mental health transportation decisions on an individual case-by-case basis. Transportation is provided for employment, visits to a therapist and for shopping and social recreation. BDS will pay for medical trips by taxi when a mental health consumer needs to arrange a doctor visit sooner than the Medicaid advance reservation limit will allow. On occasions when a case manager needs to accompany a consumer on a visit, the case manager will sometimes use his or her own car to take the consumer to the therapist's office. In-home support staff also occasionally provide rides when needed. Case managers and support staff are both reimbursed at the state mileage rate for the use of their own automobile.

While mental health case managers often arrange trips through the same providers that serve as DOT's designated regional agencies, the arrangements are ad hoc and independent of DOT and Medicaid regional coordination system.¹⁵⁶ In fact, in the past year, BDS' Region 2 office provided funds for the Mid-Coast Mental Health Center to purchase its own van to carry 8-to-10 mental health consumers to jobs. The Region 2 office is considering other similar arrangements with other provider agencies to purchase vehicles for the exclusive use of mental health consumers.

¹⁵⁴ Telephone interview with David Goddu, Financial and Resource Program Manager, BDS, May 2001.

¹⁵⁵ Telephone interview with Gene Skibitsky, Western Maine Transportation Service, June 2001.

¹⁵⁶ Telephone interviews with BDS regional managers, May 2001.

Children's Mental Health Services. These are services offered to families with children, up age 18, who have, or who are at risk for, developmental disabilities, autism, or who have been diagnosed with emotional or behavioral disorders. State rules require that transportation needs be included in each consumer's Individualized Support Plan and that the Plan provide for services to be delivered in the least restrictive appropriate environment. When consumers leave or are terminated from services, they also have the right a comprehensive discharge or service plan that includes, "assisted referral to existing resources," including transportation.¹⁵⁷

Department of Education (DOE)

The State Statutes and Rules assign to local school districts the responsibility to provide accessible transportation, to and from school, on school grounds, or to and from a special education service provider, for children between ages 5 to 20, who require special education due to a disability. If the local school district pays tuition to send such a child to another public or private school, the local district must also provide for transportation to and from that school. When necessary, schools must provide specially adapted buses or vans, lifts, ramps, or a transportation aide, as specified in the child's Individualized Education Program. Carrying a student in or out of a vehicle or building is not permitted.

If the school district asks a parent to furnish their child's transportation to school or to a special education provider, the district must reimburse the parent for mileage and other necessary travel expenses at the same travel reimbursement rates paid to school employees.¹⁵⁸

Department of Labor (DOL)

The Bureau of Rehabilitation Services (BRS) within the Department of Labor also plays a role in providing transportation services. BRS' Division of Vocational Rehabilitation (DVR) and the Division for the Blind and Visually Impaired (DBVI) can assist with transportation, including travel and related expenses that are necessary for an applicant or eligible individual to participate in post-secondary education, vocational rehabilitation services, and to get a job.¹⁵⁹

The BRS Division of Vocational Rehabilitation can also assist with motor vehicle modifications so that the car or van can be driven or ridden in by a person with disabilities. The recommended expenditure limit for DVR modification assistance is \$12,000. Depending upon the type of vehicle and the extent of modification required, the full cost of a new modified vehicle typically ranges between \$20,000 and \$80,000. Consumers who are interested in driving a modified vehicle can go to Maine's Center for Independent Living for a driver evaluation or to visit their annual modified vehicle fair.

Most major car manufacturers have adaptive equipment reimbursement programs, usually called a "Mobility Program," that typically pay up to \$1,000 for adaptive modifications to new vehicles

¹⁵⁷ "Rule Chapters for the Department of Behavioral and Developmental Services: Rights Of Recipients of Mental Health Services Who Are Children in Need of Treatment," 14-472, Ch. 1A. XII

¹⁵⁸ "Maine Special Education Regulations," Maine Department of Education Rules, 05-071, Chapter 101, Section 6.17-18.

¹⁵⁹ "Division of Vocational Rehabilitation Policy Manual," Maine Department of Labor Rules, 12-152 Chapter 1, Section 9.6.1.

whether purchased or leased. The adaptations can be installed by a dealer, or by an outside firm specializing in adaptive modifications.

Independent Efforts

In recent years, Maine has seen at least three independent efforts to create new transportation services for persons with disabilities or for the elderly. These have included:

- the Alpha One-Center for Independent Living Job Trek program;
- Rec Ride-Plus and SeaBreeze Transportation in Bangor; and
- the Independent Transportation Network (ITN), in the Portland-Westbrook area.

Of the three, only SeaBreeze and ITN are still in operation.

Job Trek

The Alpha One – Center for Independent Living Job Trek program was a three-year statewide demonstration to provide transportation resources to enable persons with disabilities to work. Between 1993 and 1996, the program accepted half of the 503 applicants and offered them individual training sessions and a consumer guide to managing transportation. Job Trek developed an Individualized Transportation Plan with each consumer and gave each consumer vouchers, called "Trip Tics," to subsidize their transportation costs. The vouchers were intended to give consumers more independence and more flexibility with transportation services. Over two-thirds of the consumers used the vouchers to participate in ride-sharing by car, 29% used fixed route buses, and 14% used paratransit or other means. (The percentages add up to more than 100% since several consumers used multiple means of transportation during the course of the program.) Despite high consumer satisfaction, reports of increased consumer independence and indications that the program had helped consumers gain or maintain employment, the program was terminated due to an inability to obtain funding beyond the initial demonstration period.¹⁶⁰

Rec. Ride Plus

Rec. Ride Plus was a Bangor-area volunteer project founded by Maine Adaptive Sports and Recreation with funding and support from the Easter Seals' Project Action and United Cerebral Palsy. Rec. Ride Plus operated a bus, two lift-equipped vans, and three automobiles, all operated by volunteer drivers. The program offered low-cost door-to-door transportation to persons with disabilities and elders during weekdays. It served 21 towns including Bangor. The project, which began in 1997, ceased operation in November 1999 due to lack of funds.

Two of the Rec. Ride Plus volunteers have since founded SeaBreeze Transportation to provide a similar service on a much smaller scale. SeaBreeze has only one van to provide rides for elderly consumers and consumers with disabilities in towns within 15 miles of Bangor. They are able to serve from 15 to 20 consumers per week and have to turn down nearly half their requests for rides each week due to lack of resources.

¹⁶⁰ Richards, Mark F., "Job Trek Final Evaluation Report," Muskie School of Public Service, (Portland, Maine: Nov. 1996)

SeaBreeze offers rides for any purpose except Medicaid trips, which are covered by another regional provider. SeaBreeze charges \$3 for one-way trips within Bangor and Brewer, and up to \$8, one-way, to serve out-lying towns. Since SeaBreeze has been unable to attract funding from government or any outside organizations, trip fees represent its sole source of revenue. It is not clear how long this service will last, since the founders report they have maxed-out their credit cards and gone deeply into personal debt to keep the system running.¹⁶¹¹⁶²

Independent Transportation Network (ITN)

ITN is the one independent volunteer transportation project in Maine that appears to be succeeding. ITN has been serving the non-Medicaid elderly and persons with visual impairments for five years in the Portland-Westbrook area. (*Note:* Since ITN is a non-union agency that receives direct grant funds from the U.S. Department of Transportation, federal law prevents them from competing for contracts with Medicaid and the other state-funded programs already served by the union drivers at the Portland-based Regional Transportation Program.)

ITN currently serves about 1,000 consumers, of whom, about 600-to-800 ride in any given month. ITN operates seven automobiles and many volunteer drivers provide their own cars. While most of ITN's riders are middle-to-upper income elders who do not qualify for ADA status, the program is very innovative and has developed some very interesting ideas that could well be adapted to improve service and consumer options among Maine's other transportation providers.

Instead of imposing strict deadlines for making reservations in advance, ITN allows members to call up to the same day, but at a cost. Riders earn a 54% discount for reserving by 6:00 p.m. the day before. This allows for much greater consumer flexibility, while using price as an incentive for advance planning. The incentive works, since 95% of all rides are reserved a day-or-more in advance.

Riders also earn big discounts by agreeing to share trips with other riders, and ITN has developed a sophisticated geographic computer database system to plan trips and to automatically recognize opportunities to schedule shared rides. At present, about 10% of all rides are shared.

In line with their consumer-oriented focus, ITN has adjusted their scheduling system to ensure a much tighter "pick-up window" than other transit providers who serve persons with disabilities in Maine. When a consumer books a ride with ITN, the ITN car will arrive no earlier or later than 10 minutes before or after the scheduled arrival time. Other providers guarantee a pick-up window no better than 30 minutes before-or-after, and there are consumer reports in some rural areas of pick-up windows as long as 2 hours before or after the agreed pick-up time.

Each rider is charged a pick-up fee of \$2.50 for rides that begin between 7:00 a.m. and 9:00 p.m. The pick-up fee increases to \$6.00 for nighttime service. The price per mile begins at \$1.85 for same-day reservations, drops to 85¢ per mile for advance reservations, and can go as low as 40¢

¹⁶¹ Averill, Joni, "SeaBreeze to Pick Up Where Rec Ride Plus Left Off," The Bangor Daily News, Jan. 8, 2000.

¹⁶² Telephone interview with SeaBreeze co-founder, Steve Look, August 2001.

per mile for booking in advance and sharing a ride with three other persons. ITN's roughly estimated average cost per round-trip is around \$30.

Volunteer drivers are reimbursed at 25¢ per passenger mile, or they can receive mileage credits in the ITN "Roads Scholarship Fund." Drivers who accumulate mileage credits can cash them in toward free trips from themselves or others. Volunteers also receive a mileage credit for driving unoccupied miles. However, nearly four-fifths of the drivers donate their reimbursement fees and credits back to the organization.

In addition to start-up funding from the Federal Transit Administration and Transportation Research Board, ITN has managed to attract grants and funds from a variety of national and local non-profit organizations and foundations including AARP, the Great Bay Foundation, and Maine Bank and Trust. ITN's innovations and consumer focus have also attracted attention from many national publications, including U.S. News and World Report.

While ITN's founder, Katherine Freund, intends to replicate the program in other areas across the country and elsewhere in Maine, ITN does not intend to seek state funding or additional federal grants. Freund believes that government funding for operations like hers should be limited to start-up purposes, and that continued government funds would divert scarce resources from more traditional providers who serve the consumers of state-funded programs. However, Freund and ITN would be willing to share ideas and make ITN's next-generation software system available to other Maine transit providers.¹⁶³

Transportation Options

There are a variety of transportation services, supported by local communities, regionally, and by the state and federal government. These services are outlined below:

- fixed route public transportation;
- demand-response paratransit;
- volunteer drivers;
- mileage reimbursement to families, neighbors and friends;
- taxis; and
- private vehicles modified for accessibility.

Fixed-Route Public Transportation

While the term "fixed route public transportation" usually refers to city or regional bus systems, it can also refer to scheduled van service, or to ferries. Portland, South Portland, Bangor-Orono, Lewiston-Auburn, Biddeford-Saco-Old Orchard Beach, and Augusta-Waterville are all served by urban fixed route bus systems that run daily or all weekdays. Eighty percent of the purchase cost for new vehicles is paid for by federal funds with state and local sources paying the remaining 20%. Operating expenses are paid by passenger revenues, rider fees paid by Medicaid and other state programs, and local subsidies.

¹⁶³ Telephone interview with Katherine Freund, Independent Transportation Network, May 2001.

Typically, fixed route transportation serves the general public, charging a fee for use. The Americans with Disabilities Act (ADA) applies to publicly financed fixed-route service. The transportation regulations for the ADA require all new buses and vans to be equipped to accommodate wheelchairs. The ADA regulations also require fixed route public transit buses to deviate from their regular route to pick-up or drop-off a person who, by reason of a disability, cannot get to or use the regular bus stop. Requests for route deviation usually must be made at least the day before and the ADA requires buses to deviate at least three-quarters of a mile on either side of the regular route, or three-quarters of a mile beyond either end-point of the route.

Demand-Response Paratransit

Demand-response paratransit is a door-to-door service usually operated with vans or small buses. Rides are arranged by phone in advance. This section describes:

- ADA paratransit service;
- non-ADA paratransit service; and
- paratransit operations.

ADA Paratransit. The ADA requires all fixed route public transit providers to offer or arrange for paratransit service for any person who, due to a disability, cannot use the regular fixed route bus. The qualifying disability need not be physical. For example, fixed route public transit providers must also provide a paratransit alternative for persons whose cognitive or developmental disability makes it difficult for them to navigate a route or make the appropriate bus transfer. Public transit providers may offer rider-training programs to consumers with disabilities who want to learn how to take the fixed route bus. However, the consumer has the right to turn down the offer and to continue to use the paratransit service instead. If successful training or the nature of a consumer's disability allows them to use some fixed routes, but not others, the transit provider must serve the consumer with paratransit service on those other routes.

The ADA requires that the paratransit option must offer a level of service that duplicates the fixed route service. The paratransit vans must cover the same areas served by fixed route buses, and offer the same hours of service. The fees charged for paratransit service are limited to no more than twice the fare charged for a similar trip at the same time of day on the fixed route service. Fixed route transit providers cannot limit the number of paratransit trips offered to a qualifying individual and cannot restrict the purpose for taking a paratransit trip. The ADA requires that the paratransit operator must accept reservations up to any time during the transit operator's regular business hours of the day before the requested ride. Operators sometimes accept same-day requests if they can fit them into the existing schedule. Although the ADA rules are not specific, paratransit operators cannot require consumers to accept unreasonable pick-up windows (the number of minutes a consumer is required to be ready to leave before or after the scheduled pick-up time), and operators must maintain a reasonable level of on-time performance,¹⁶⁴ although the definitions of "reasonable" and "late" are still being decided by the courts.

¹⁶⁴ Title 49 Code of Federal Regulations, Part 37, Section 131.

Non-ADA Paratransit. Demand-response van service is not limited to the ADA paratransit service that is meant to supplement fixed route city bus systems. Many smaller towns and rural areas have reservation-based, flexible-route, fixed-schedule van or bus service once-or-twice a week, or sometimes once a month. For example, the Aroostook Regional Transportation System operates a mini-bus service within Caribou, Fort Kent, Presque Isle, and Houlton five-days-a-week, but the surrounding towns for each of those areas are served by flexible route scheduled service once-or-twice-a-week. Limestone, Loring, and Caswell are served every Tuesday and on every third Wednesday of the month by a bus that leaves Presque Isle around 9:00 A.M., arrives in Caribou at 11:00, and makes the return trip in the mid-afternoon.¹⁶⁵ These non-ADA services are not required to meet the same scheduling and performance standards that the larger city systems do.

Paratransit Operations. For purposes of planning and route efficiency, paratransit operators generally group requests into three categories, subscription rides, advance reservation rides and same-day requests. A subscription is a standing reservation for a regularly repeating trip, be it a ride to work Monday-through-Friday, weekly dialysis treatments, or a trip to the supermarket every Tuesday and Friday.

From the operator's point-of-view, subscription rides form the core of an efficiently planned van schedule. Operators usually plan their basic routes and schedules around the subscription base. For example, a provider might build their basic schedule around subscription trips for people leaving outlying areas to come into the city to go to work and to day programs in the early morning, gradually fill the mid-morning schedule with advance reservation trips around town, schedule mostly subscription rides to-and-from a local senior center at lunchtime, schedule more advance reservation trips in the mid-afternoon, and finish with subscription rides from work and from day programs at the end of the day. Operators will often accept same-day requests, but only if they can fit the rides into the existing routes and schedules.

Volunteer Drivers

Volunteer drivers play a vital role in Maine's system of transportation for persons with disabilities. Volunteers offer rides in their own cars and are typically reimbursed at the state mileage rate. These drivers are organized, scheduled and reimbursed through the regional and local transportation providers. In urban paratransit systems, volunteers take many of the rides that cannot be fit into the schedule of vans and paid drivers. In small towns and rural areas where distances are long and it is harder to group rides together, they offer much of the non-emergency medical transportation to doctors' appointments and other types of Medicaid-covered care. In Washington and Hancock counties, volunteer drivers provided 29% of all Medicaid rides in fiscal year 1999 at an average distance of 36 miles per trip, each way.¹⁶⁶

Although the large majority of volunteer rides are reimbursed by Medicaid, volunteers also provide rides for a wide variety of other, non-Medicaid social services.

¹⁶⁵ "Caribou Area Bus Schedule," Aroostook Regional Transportation System, Inc., (Presque Isle, ME: November 1997).

¹⁶⁶ Washington Hancock Community Agency, "MDOT Region 2 Biennial Operations Plan", 2001, p. 14.

While volunteer drivers were once relatively easy to recruit, low unemployment rates and rising gasoline prices over the past few years have made it harder to find enough willing volunteers to meet the demands. Several Maine transportation providers have recently reported that they have far fewer volunteer drivers than they had five years ago and that this situation has worsened with this spring's rapid rise in gas prices.

Mileage Reimbursement to Families, Neighbors and Friends

Medicaid also subsidizes the cost of personal transportation to non-emergency medical appointments and other Medicaid services. Medicaid subsidizes the cost by paying 15¢ per mile to Medicaid beneficiary, family member, neighbor, or friend who provides the ride. Medicaid reimbursement is limited to the number of miles it takes to drive the shortest distance to the nearest appropriate Medicaid provider.

Taxis

Taxis tend to be the high-cost method of last resort. If there is no other way to get a person to Medicaid appointment, or if no van is available to deliver a promised ride to an ADA paratransit passenger, an agency will hire a taxi to provide the service.

Private vehicles modified for accessibility

There are several sources of funding to help pay the cost of modifying a personal automobile or van to accommodate the needs of a driver or passenger with disabilities. Modifications may include a wheelchair lift, replacing foot pedals with hand controls, or moving all hand controls to one side of the steering wheel. The typical cost for a new vehicle with modifications can range from \$18,000 to \$80,000. Maine's Center for Independent Living provides an evaluation and consulting service to help drivers with disabilities choose the most appropriate modifications.

All major domestic and many foreign car manufacturers have accessibility programs that pay up to \$1,000, and sometimes more, toward the cost of modifications for new cars, whether performed by a dealer or outside specialist.

Maine's MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program (AELP), established in 1988, funded by State bonds and administered by the Finance Authority of Maine, is a \$6.5 million low-interest loan fund to help finance adaptive modifications to vehicles and homes.

The Maine Department of Labor's Independent Living Services program, administered through Maine's Center for Independent Living, has the authority to provide grants for vehicle modifications. However, the program has a long waiting list and first priority goes to persons with disabilities in immediate jeopardy of moving to more restrictive environment, or to enable people to move to a less restrictive environment. Transportation is rarely the immediate key issue in either of those situations.¹⁶⁷

¹⁶⁷ Telephone interview with Brad Strause, Alpha One, May 2001.

Other Transportation Sources

In addition to Medicaid and directly-state funded trips, consumers with disabilities and other Mainers can also pay for trips, almost always at well below cost, that are offered by the regional public transit agencies and other non-profit and for-profit transit services. These rides can be used for any purpose including work, shopping, senior meal centers, recreation and social activities.

However, availability is particularly limited in many rural areas. While the Portland METRO bus service and Regional Transportation Program (RTP) operate every day of the week and on weekdays until 10:00pm, the majority of towns in rural areas are served only once a week and some only once or twice a month.

Other Steps and Measures

DOT Analysis of Transit Provision in Maine

In the past year, the DOT's Office of Passenger Transportation has begun a Transit Study to assess system adequacy and measure existing levels of service, total transit need, and unmet need in different geographical areas of the state by different groups including the elderly and persons with disabilities. However, addressing the needs of persons with disabilities is just one goal among many others including:

- developing better connections between different modes of transportation including planes, boats, trains and buses;
- expanding public transportation options for tourism; and
- meeting federal requirements to reduce air pollutions and overall vehicle emissions by encouraging commuting by transit instead by automobile.¹⁶⁸

¹⁶⁸ "Office of Passenger Transportation: Transit Study", Office of Passenger Transportation, DOT website, <http://www.state.me.us/MDOT/opt/ts/tshome.htm>.

Employment

For most of us, our jobs are an important part of our lives. Because we spend a large amount of our time at work, most of us want our work to be meaningful and just about all of us expect to be paid appropriately for our work. For numerous reasons, many people with disabilities have not been able to expect the same rewards from employment. Many people with disabilities have had to struggle to be part of the workforce. With some statistics placing the unemployment rate for people with disabilities above 70%, unequal access to employment and earned income means impoverishment and dependency on public or private support, as well as the exclusion from full participation in the community. Persons with severe disabilities who do work earn 60¹⁶⁹ percent of that earned by persons without disabilities. This section reviews the factors influencing the employment of persons with disabilities, focusing on state and federal laws and programs, as well as other factors. This section describes:

- the role of state agencies; and
- the role of other laws, programs and initiatives.

The Role of Federal and State Employment Law

Many state agencies provide employment support and related services for workers with disabilities. Maine agencies addressed specifically in this next section are the Department of Labor (DOL), the Department of Education (DOE), the Department of Behavioral and Developmental Services (BDS), and the Department of Human Services (DHS). As discussed below, these state agencies play a role in carrying out key federal laws related to employment.

Department of Labor (DOL)

Maine's Bureau of Rehabilitation Services (BRS), within DOL, plays several roles supporting employment for persons with disabilities. Addressed here are:

- vocational rehabilitation services;
- personal care services; and
- the Workforce Investment Act of 1998 (WIA).

Vocational Rehabilitation Services. Maine's vocational rehabilitation (VR) services are part of a federally and state-funded program. Vocational rehabilitation services began in the 1920's as part of an effort to assist veterans of World War I. This program is often called "VR" or "Title I," after the authorizing statute, Title I of the Rehabilitation Act of 1973, as amended.

In recent decades vocational rehabilitation services have been significantly affected by the emergence of the civil rights movement in this country. With revisions in the Rehabilitation Act in 1973, 1978, and 1986 and with the enactment of the Americans with Disabilities Act (ADA) in 1990, the scope of the vocational rehabilitation programs and services have greatly expanded.

¹⁶⁹ Calculated using the U.S. Census Disability Data from the Survey of Income and Program Participation (SIPP), Employment, Earnings and Disability Tables accessed 7/10/02 at <http://www.census.gov/hhes/www/disable/dissipp.html>.

We now have a national policy commitment toward the elimination of discrimination toward people with disabilities through both the Rehabilitation Act and the Americans with Disabilities Act. This change in values has led to a focus on providing services to individuals with the most severe disabilities before anyone else. A new section contained in the Rehabilitation Act Amendments of 1992 and its legislative history clearly tie the overall purpose of the Act generally, and the state program specifically, to achieving the goals and objectives of the ADA. These sections state that it is the policy of the United States that state rehabilitation programs shall be carried out in a manner consistent with the principles of presumed ability, integration and inclusion, full participation, meaningful and informed choice, and involvement of families and natural supports. These amendments provide for a fundamental change in the relationship between people with disabilities and the vocational rehabilitation counselor.

Maine's VR services are provided under two separate programs administered by two divisions within the Bureau of Rehabilitation Services, the Division of Vocational Rehabilitation (DVR), and the Division for the Blind and Visually Impaired (DBVI). Both of these agencies help people with disabilities gain or maintain full or part-time employment in a competitive and integrated job setting, or to become gainfully self-employed. DVR administers the General Vocational Rehabilitation program and DBVI administers the Blind Vocational Rehabilitation program. Here both programs are described collectively as VR services.

Population Served. Together the DVR and DBVI programs serve about 6,700 adults with disabilities at any given time. About 40% of the persons served have a physical or orthopedic disability, about 30% have been diagnosed with mental illness, and 11% are blind or seriously visually impaired. VR also serves persons with other disability diagnoses, such as mental retardation, deafness, head injury, or an addiction disorder.

Services. The program offers job-seeking assistance, training and educational opportunities including post-secondary training, job coaching, home modifications, adaptive devices, assistive technology, and the basic tools, equipment and uniforms required to begin or obtain a job. Once a person has received services and has obtained employment, a job coach may provide support and on-the-job training until the participant has learned all the needed skills. The participation of the job coach may vary from brief monthly contacts to daily support.

Vocational rehabilitation services end when participants have maintained employment for at least ninety (90) days after the transition to extended services and have earned at least minimum wage in an integrated setting. Post-employment services are available on a short-term basis to an individual after VR services end, if that individual needs services to "maintain, regain, or advance in employment."

Funding. Approximately 80% of the costs of Maine's Vocational Rehabilitation program are federally funded, with the rest of the funds provided by the state. Services and supports are offered free of charge to participants.

Eligibility Criteria. The general criteria for participation in the program are that an applicant has a disability that prevents him or her from obtaining or keeping employment, and that vocational

rehabilitation services are necessary to obtain and keep a job.¹⁷⁰ Supplemental Security Income (SSI) recipients and Social Security Disability Insurance (SSDI) beneficiaries are presumed to be eligible. Eligibility is not based on financial need.

The process begins with the process of determining eligibility. People with disabilities are presumed to be eligible for services and are assumed to be capable of working unless a rehabilitation counselor can clearly and convincingly demonstrate otherwise. Congress now expects the primary effort of the vocational rehabilitation counselor will not be to make eligibility determinations, but rather to identify and arrange for needed services and to conduct job development and placement activities. With this presumption of ability, it is clear that most people with disabilities can achieve employment and other vocational goals if appropriate services and supports are available to them.

Assessment of Need. The vocational rehabilitation counselor performs an assessment of each participant's vocational interests, employment skills, work experience, and the state of the current job market in relation to the participant's preferences and abilities.

Planning. Using the findings of a comprehensive assessment phase, an employment plan, called an Individualized Plan for Employment (IPE), is developed. The IPE is developed together by the consumer and a vocational rehabilitation counselor, and at times with assistance from other representatives selected by the individual. Alternatively, the individual can develop his/her own plan. The employment plan identifies the individual's long-term vocational goals, the services necessary to reach those goals, how each step will be evaluated, and consumer views and comments about the plan. The plan includes all services to be provided to meet employment goals, regardless of which agency makes them available. Vocational rehabilitation services are tailored to the consumer's employment goals in consideration of the individual's strengths, resources, priorities, concerns, abilities and capabilities. The employment plan also describes how the individual was involved in choosing among alternative goals, objectives, services and service providers. Both the counselor and the consumer must sign the IPE, which is to be reviewed every twelve (12) months.¹⁷¹

Delivery of Services. Vocational rehabilitation services are provided through a variety of public and private providers. DOL staff includes rehabilitation counselors, who provide vocational guidance and counseling services, plus other vocational support staff working out of the CareerCenters. A wide range of other vocational support services, including job development and job coaching, are contracted through non-profit providers. Vocational rehabilitation services include support for people choosing self-employment. DVR will assist with the development of a feasible business plan, securing loans, etc. DVR limits its financial support to \$5000, with some exceptions for self-employment.

Extended Employment Support. Individuals who need employment supports beyond 90 days may be eligible for extended employment services. In order to be eligible, the individual must

¹⁷⁰ DOL Rule, 12-152 CMR Chapter 1, Section 5.2.

¹⁷¹ More detail on this is available from the Consumer's Guide to Maine's Vocational Rehabilitation Programs, available online at <http://www.caresinc.org/docs/vrguide/index.htm>.

- have a severe disability that interferes with that person's ability to obtain or keep employment;
- require ongoing supports to maintain employment; and
- have a reasonable likelihood of funding to ensure employment support beyond VR services. Funding may be available to individuals through BDS, BFI and other sources.

Extended support, or long-term support, usually refers to the following types of service, sometimes collectively referred to as “job coaching”:

- On-site task supports (instructing, modeling, social skill instruction);
- Off-site supports (counseling, case-management, & collateral contact);
- Accommodation development/ job development (task / job analysis);
- Co-worker site development;
- Report writing / record keeping;
- Employment preparation; and
- Assessment (job shadowing, tours, & situational assessments).

Feedback on Consumer Satisfaction with VR Services. The 1992 Amendments to the Rehabilitation Act mandate state Rehabilitation Councils to conduct annual surveys of consumer satisfaction. Maine’s DVR conducts a periodic “Satisfaction and Outcome Survey” that is mailed to all clients who are closed after eligibility is determined. The current survey instrument has been in use for 3 years. Findings from the 1999 survey reported average satisfaction findings with aspects of DVR service, including consumer choice (4.1, on a scale from 1 being not satisfied to 5 very satisfied), access to services (3.9), and service outcome (3.9)¹⁷².

The Client Assistance Program (CAP). The CAP is a federally funded advocacy program for applicants/consumers of Vocational Rehabilitation, Independent Living Service and other programs of the Rehabilitation Act. CAP provides information/referral, consultation/advice and/or representation to eligible individuals. Persons who do not understand the IPE, have questions about their rights, or receive an adverse decision from BRS can contact the CAP for assistance. In Maine, the CAP is operated by C.A.R.E.S., Inc.¹⁷³

Personal Assistance Services (PAS). As of July 2002, BRS oversees three consumer-directed personal assistance programs for adults with disabilities, without which many individuals with disabilities would not be able to work and live independently in the community. These services are funded through the MaineCare program and with state funds. Employment supports, such as getting ready for work and performing employment tasks, including having a PAS in the workplace, are not currently funded by these programs. More information on PAS services as provided now, and as they are being studied in relation to support for employment, is provided in the section below on Personal Assistance Services.

¹⁷² Summary prepared for Maine State Rehabilitation Council, undated, provided by fax by Art Jacobsen, DVR.

¹⁷³ More information available on the Internet at <http://www.caresinc.org/>.

Workforce Investment Act of 1998 (WIA). The Workforce Investment Act of 1998 (WIA), which included the Rehabilitation Reauthorization, provides the framework for a national workforce preparation and employment system and funds a number of employment and training programs across the nation. The primary purpose of the WIA is to increase the employment, retention, skills and earnings of participants. Effective July 1, 2000, WIA replaced the Job Training Partnership Act (JTPA), the 1982 Federal law which created, directed and financed the nation's single largest employment and training program.

In Maine, the WIA law has supported the development of 23 CareerCenters across the state. These centers are to be governed by the philosophies of:

- universal access;
- customer choice;
- program integration; and
- accountability.

Under WIA, these one-stop centers integrate employment services so that there is “no wrong door”—no matter where a person starts, he or she should be able to find the right source of help or training. Programs administered through the CareerCenters include those for people with disabilities and programs for other population groups.

Department of Behavioral and Developmental Services (BDS)

BDS provides extended employment support for workers with disabilities when the following criteria are met:

- the person is eligible for mental health or mental retardation services;
- the person needs employment supports;
- services are available; and
- funding is available.

In 1999 the Maine Medical Center conducted a “program audit” of BDS practices in planning and delivering vocational services. The audit included about 100 interviews with a diverse group of people. Data from these interviews was organized into a report containing 17 specific recommendations.¹⁷⁴ Recommendations included the development of a vocational policy. This policy was adopted in November 2000.

BDS supports self-employment through its Mental Health Long-Term Support Program. After transitioning from the vocational rehabilitation plan, a person may have access to the support services of a business coach, as resources permit.

¹⁷⁴ Making the Connection: Coordination of Integrated Vocational Services, Maine Medical Center, Department of Vocational Services. August 1999.

Department of Education (DOE)

Maine DOE oversees both regular and special education systems that serve individuals with disabilities in public and private schools at various levels. It provides a critical support role to schools as they prepare youth with disabilities for future independent work and life in the community. The DOE focuses its vision for Maine's education system through learning standards which are defined in its "Learning Results" document. On the six "Guiding Principles" of the document, the fourth principle is as follows:

"Each Maine student must leave school as A COLLABORATIVE AND QUALITY WORKER

1. knows the structure and functions of the labor market;
2. assesses individual interests, aptitudes, skills, and values in relation to demands of the workplace; and
3. demonstrates reliability, flexibility, and concern for quality.¹⁷⁵,

Two key federal laws provide the structure for much of DOE efforts to meet the Learning Results standards for Maine's citizens with disabilities:

Individuals with Disabilities Education Act Amendments of 1997 (IDEA). The Individuals with Disabilities Education Act (IDEA) is the current federal education law for individuals with disabilities (the former law was P.L. 94-142, the Education for All Handicapped Children Act of 1975). The purpose of IDEA is to ensure that all eligible children with disabilities have access to a free appropriate public education (FAPE) with services designed to meet their unique needs and to prepare them for employment and independent living. IDEA requires public schools to provide a free appropriate public education in the least restrictive environment appropriate to their individual needs. It also requires public school systems to develop appropriate Individualized Education Programs (IEPs) for each child.

The IDEA law better defined school's role in preparing the student with a disability for life in the community, including addressing employment goals and vocational supports. Beginning at age 16 (or younger, if determined appropriate by the student's IEP team), a young person's IEP must include a statement of needed transition services, including, when appropriate, a statement of interagency responsibilities, or any needed linkages, or both. "Transition services" includes instruction, related services, community experiences, the development of employment and other postschool adult living objectives, and when appropriate, acquisition of daily living skills, and a functional vocational evaluation.

The Carl Perkins Vocational and Applied Technology Education Act. This law recognizes that vocational education offers unique benefits for many youth with disabilities. Under this law, youth with disabilities must be provided the same opportunity as all other youth to enter vocational education. Local school districts, area vocational schools, and other agencies that receive funding under this law must provide information to special populations including youth with disabilities about vocational education opportunities at least one year before they are eligible for such opportunities, or as indicated by their Individualized Education Program (IEP).

¹⁷⁵ Maine's Learning Results: High Standards for All Students, originally published July 1997 and available for viewing on the Internet at <http://www.state.me.us/education/lres/lres.htm>.

Schools must provide youth with disabilities with supplementary and support services necessary for their success in vocational education. These supports include curricula, assistive technology, equipment, classroom modifications, supportive personnel, and instructional aids and devices.

Department of Human Services (DHS)

Medicaid Option for Workers with Disabilities. Maine was one of the first states to take advantage of a new federal option to allow persons with disabilities to retain important health insurance through Medicaid when earnings increase from employment. Under this new option (sometimes referred to as the “Medicaid Buy-In” program), individuals with disabilities can earn up to 250% of the Federal Poverty Level and still keep Medicaid benefits. Most importantly, this new option covers individuals with disabilities who are eligible for Medicaid from a state-funded Medicaid option, and as such were not eligible for the federal “section 1619(b)” program which protects Medicaid benefits for SSI recipients. Since this eligibility option was first available in August 1999, over 900 workers with disabilities have participated in the buy-in option. More information on this option is provided in the section below on Medicaid.

Personal Assistance Services (PAS). DHS also oversees and funds agency-based personal assistance services in Maine, without which many individuals with disabilities would not be able to work and live independently in the community. These programs are funded through the MaineCare program, and other state-funded programs such as Home Based Care. Employment supports, such as getting ready for work and performing employment tasks, including having a PAS in the workplace, are not currently funded by these programs. More information on PAS services as provided now, and as they are being studied in relation to support for employment, is provided in the section below on Personal Assistance Services.

Maine Works for Youth! The Maine Works for Youth! (MWY) is a collaborative venture between the DHS Bureau of Health and the Center for Community Inclusion (CCI). It continues the work of the Maine Adolescent Transition Partnership, with the goal of developing a statewide structure to ensure that adolescents with special health care needs, including disabilities, will transition smoothly to post secondary educational programs, employment, and adult living with the services and supports they require to lead successful, meaningful and inclusive lives in the communities of their choice.

In an earlier needs assessment phase conducted under the Maine Adolescent Transition Partnership (1996-97), the employment needs for youth with disabilities were identified, including:

- employers don’t know how to access adolescents with special health care needs/disabilities;
- need for education about how to meet the accommodation needs of adolescents with special health care needs/disabilities; and
- networking and ongoing training are critical for successful employment.

The Role of Other Laws, Programs and Initiatives

This section examines the role that other federal and state laws, programs and initiatives play in promoting or discouraging employment for people with disabilities in Maine. These are:

- Social Security;
- Medicaid;
- The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA);
- The Americans with Disabilities Act (ADA);
- Disability benefits for workers;
- Personal assistance services;
- The MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program; and
- The DVR/BDS Central Office Group

The Federal Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA)

The new TWWIIA legislation is seeking to address job benefit incentives, including health insurance, the provision of personal assistance services for workers with disabilities, and the development of additional career and job development system resources. The details on this law are presented in that paper separate from the individual state agencies, since it involves each of these agencies, as well as the Social Security Administration.

This new law:

- increases access to, and beneficiary choice in obtaining, rehabilitation and related vocational training and placement services;
- provides new incentives and grant funds to states to use to enhance or create Medicaid buy-in programs for workers with disabilities, so that income from a job does not jeopardize health care coverage for workers disabilities:
 - States have the option to provide Medicaid coverage to more people with disabilities aged 16-64 who work,
 - States have the option to permit working individuals with incomes above 250 percent of the federal poverty level to buy into Medicaid, and
 - Provides states with grant funds for state Medicaid Infrastructure Grants;
- provides new work incentives for individuals in two key SSA programs, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), including:
 - Provides expedited reinstatement of benefits for individuals whose benefits have ended because of earnings from work,
 - Places certain limits on Continuing Disability Reviews for individuals on SSDI, and individuals on SSI or SSDI who are using a Ticket to Work,
 - Directs SSA to conduct a demonstration project to reduce the “earnings cliff” faced by individuals on SSDI who lose benefits due to increased job earnings, and
 - Provides an extended period of Medicare eligibility, up to 8 ½ years of premium free Medicare Part A benefits to SSDI beneficiaries who lose cash assistance because they return to work; and

- assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits.

Four key TWWIA initiatives that are taking place in Maine are described in detail below.

The Ticket to Work. The Ticket to Work program is intended to expand the range of employment service options for participants in the Social Security’s SSDI and SSI programs. Through the Ticket Program, individuals with disabilities can receive job-related training and placement assistance from an approved provider of their choice. This provision enables individuals to go to providers whose resources best meet their needs, including going directly to employers. Ticket are taken to an Employment Network which includes both private organizations or public agencies, including the State Vocational Rehabilitation Agency, that have agreed to work with Social Security to provide services under this program.

CHOICES. Maine CHOICES (Continuing Health Options and Incentives via Coordinated Employment Supports) is a Medicaid Infrastructure Grant project that builds on the strength of Maine’s current Medicaid Buy-in Program. Maine CHOICES undertakes a significant multi-year research, program development and partnership-building initiative. Its goals are:

- to improve access to competitive employment for people with disabilities;
- to advance technical understanding of how MaineCare-funded services specifically support the competitive employment of people with disabilities, and to devise equitable and effective methods for targeting MaineCare resources to that end;
- to improve the coordination of multiple policies and programs available to support competitive employment among people with disabilities; and
- to increase collaborative efforts with other states to promote employment of people with disabilities.

Alpha One’s “Ability First” Project. This project operates under the policy umbrella of the TWWIA law as well. Project partners include Alpha One, Training Resource Center (TRC - Portland), six other CareerCenters within the southern portion of Maine's One-stop system, and the Bureau of Rehabilitation Services.

The Ability First project approach includes:

- emphasis on consumer direction in employment services;
- CareerAble, self-directed evaluation and skills inventory package for consumers with disabilities;
- expanded access to employment supports Benefits Counseling;
- upgrading of adaptive equipment/assistive technology in CareerCenter computer labs;
- Technology Training Fund to upgrade skills of consumers with disabilities;
- increased assistive technology utilization training for teachers; improved outreach to and relationships with employers; and
- supplemental human resources capacity services provided to employers around disability issues.

Social Security Benefits Planning. With funds provided through the TWWIA law, Social Security Administration in 2001 awarded Maine Medical Center (MMC) a Benefits Planning, Assistance, and Outreach (BPAO) Program grant, with the goal of better enabling Social Security Administration beneficiaries with disabilities to make informed choices about work. MMC's ABC Ticket to Work Benefits Planning Program will hire three Benefits Specialists, who will:

- provide work incentives planning and assistance to SSA's beneficiaries with disabilities;
- conduct outreach efforts to those beneficiaries (and their families), who are potentially eligible to participate in Federal or State work incentives programs, and
- work in cooperation with Federal, State, and private agencies and nonprofit organizations that serve beneficiaries with disabilities.

To extend the range of benefits counseling activities in Maine to address the entire state, the Department of Labor has provided additional state funds for two more benefits counselors. One of these will be housed with the Alpha One office in Brewer to assist in covering the northern parts of the state. Additionally, the Disability Rights Center (DRC) is funded under the Social Security Act to provide individuals with protection and advocacy services for issues related to TWIAA benefits.

Social Security

The Social Security system has served as a major barrier to successful employment and careers. In the early days of Social Security, and even for some of the more recent Social Security Administration (SSA) programs, it was assumed that a disability prevented a person from working. Conversely, if you were working, it was assumed that you were not disabled. Over time, SSA policies have changed to allow benefits to continue when working or making the transition from Social Security to earned income.

The role of the social security system has been more and more of a policy focus in the past decade. In the early 1990's some additional tools were developed, including the Impairment-Related Work Expenses (IWRE),¹⁷⁶ and Plan for Achieving Self-Support (PASS).¹⁷⁷ Those work supports did little to improve the employment statistics for people with disabilities, which has been estimated to be less than ½ of 1% for individuals receiving Social Security Disability Insurance (SSDI), and slightly higher for those receiving Supplemental Security Income (SSI). Thus there is more attention now on the disincentive effects of key social security policies, particularly the Substantial Gainful Activity (SGA) limit,¹⁷⁸ the difficulties faced by individuals who lose their job and seek reinstatement of Social Security benefits, and the overall traditional

¹⁷⁶ Allows the costs of certain impairment-related equipment and services to be deducted from gross earnings from work when calculating Substantial Gainful Activity (SGA). For more information see SSA's 2001 Red Book on Employment Support.

¹⁷⁷ Allows someone in the SSI program to set aside income and/or resources for a specified time for a work goal. These resources are then not counted when determining initial and continued eligibility for SSI.

¹⁷⁸ Under SSA programs, disability limits the ability of someone to work and earn money, termed by SSA as "substantial gainful activity." Earnings limits have been set, called SGA limits, and if a person works more than these SGA limits, SSA can use this to decide that the person is no longer disabled under the law, and thus not eligible for continued SSA disability benefits.

perspective that individuals with disabilities who are in the social security system are unable to work. These issues are addressed within the new TWWIA law, explained in more detail earlier.

Medicaid

The risk of losing health insurance has been another significant disincentive to employment. Health insurance through Medicaid is provided for all recipients of Supplemental Security Income (SSI), and Medicare is provided for all beneficiaries in the Social Security Disability Insurance (SSDI) program. When the SSI program was first created, few people would move into jobs because the increased income would make the person ineligible for continued Medicaid. The Section 1619(b) program, which protects Medicaid eligibility for SSI recipients who get a job and increase their earning, was enacted in 1987.¹⁷⁹

Recent federal options have been developed to encourage states to enact initiatives that go far beyond the 1619(b) program in protecting Medicaid and other health insurance for individuals with disabilities who return to work. Maine was one of the first states to enact a Medicaid “buy-in” eligibility option under the federal Balanced Budget Act of 1997. Under Maine’s buy-in program, eligibility extends to individuals who receive MaineCare and have income in excess of the federal limits for the Supplemental Security Income (SSI) program (and are thus not protected by the federal “section 1619(b)” program. Since this eligibility option was first available in August 1999, over 900 workers with disabilities have participated in the buy-in option.

Maine is analyzing the operation of the current Buy-In policy, and exploring the cost and feasibility of possible buy-in program enhancements, through the CHOICES MaineCare Infrastructure Grant mentioned earlier.

In addition to various medical and related health services, MaineCare can also pay for other services and equipment that can not only make work possible, but can make a key difference in the employment success of a worker with a disability. MaineCare can pay for durable medical equipment that can include assistive technology (AT), such as power and custom-made wheelchairs, augmentative communication systems, and many other similar items which are medically necessary.

Americans with Disabilities Act (ADA)

This national law has been called the largest and most significant Civil Rights law ever enacted. The law, which took effect July 26, 1992, prohibits private employers, state and local governments, employment agencies and labor unions from discriminating against qualified individuals with disabilities in job application procedures, hiring, firing, advancement, compensation, job training, and other terms, conditions and privileges of employment.

¹⁷⁹ Section 1619(b) allows an individual, who was eligible for an SSI cash payment for at least one month, to continue Medicaid coverage even when earnings from a job become too high for continued SSI cash payments. Thus the person going to work does not face a loss of income (wages replace SSI payment dollar for dollar) or a loss of Medicaid health insurance.

The ADA helps protect consumers from discrimination related to a disability. Disability under the ADA is defined broadly as either:

- a physical or mental impairment that substantially limits one or more major life activities of such individual;
- a record of such impairment; or
- being regarded as having such an impairment.

In relation to employment, the ADA holds that a person with a disability:

- cannot be fired just because of a disability;
- has certain rights when applying for a job;
- has certain rights when working at a job; and
- has certain rights even when they are fired.

Also, the ADA says that an employer may have to make changes to a job or work place to make sure that a person with a disability is treated fairly:

- when applying for a job;
- when being recruited for or offered a job;
- in doing the important parts of a job; and
- in training, leave and other benefits so that the person with a disability receives the same benefits as everyone else.

Complaints under the ADA can be made to the Equal Employment Opportunity Commission (EEOC) within 180 days of when the problems first started to happen. Action can be later pursued in court.

One key limit of the ADA is the exclusion of small businesses (those with fewer than 15 employees) from the employment discrimination prohibitions of the law. This has a particular impact on the law's effectiveness in Maine, where 84 %¹⁸⁰ of businesses are small businesses with fewer than 15 employees.

However, employees are afforded a measure of protection because the Maine Human Rights Commission enforces anti-discrimination laws with all employers, regardless of business size. The Commission investigates complaints of unlawful discrimination in employment, as well in other areas such as housing, education, and access to public accommodations. Maine's Human Rights Act, 5 M.R.S.A. § 4571, defines the "right to freedom from discrimination in employment" for individuals with disabilities. The prohibitions against discrimination employment apply to all Maine employers, regardless of number of employees.

¹⁸⁰ *Oral communication.* Janet White, Sr. Research Analyst, Maine Department of Labor, Labor Market Information Service, December 2001 data from ES 202 Covered Employment and Wages Program. 39,465 businesses with fewer than 15 employees out of 46,751 total businesses.

Disability Benefits for Workers

There are many disability-related benefit programs offered to workers regardless of disability status, to insure against injury that prevents the individual from further work and income. These programs include Short-Term Sickness and Disability Benefits, Workers Compensation, Long-Term Disability Insurance, and Social Security.

Most of these programs are defined as “income support programs,” and as such have a different purpose than Vocational Rehabilitation and other efforts to help a person return to work. They help workers and their families to cover living expenses in the event of loss of ability to work, at times while various retraining or other return to work efforts are attempted. As such, however, such income-support programs sometimes are seen as disincentives for returning to paid work, or alternatively as too limited and punitive, not providing enough income support or for as long a time as needed by a worker who experiences an accident or injury.

The following employment disability benefit programs serve workers who are not disabled as well as workers who are:

Short-Term Sickness and Disability Benefits. This mostly includes coverage for temporary illness, injury or disability for workers who are expected to return to their jobs. About 44% of private sector employees are covered by some type of short-term disability program. About 30% of private sector workers, however, do not have any formal sick leave or short-term disability income protection¹⁸¹.

Workers Compensation. Maine, and each other state, has its own Workers Compensation system, which is financed by insurance premiums paid by employers. About 87% of all American workers are covered by this program, which pays for health care and cash benefits for workers injured on the job⁸.

A key issue in Workers Compensation programs is the policy and services provided around return to work. Much research has shown the benefits of providing early intervention and significant supports that help an individual return from an injury and return to work, even if the injury resulted in a significant disability for the worker. However, there is an obvious financial interest on behalf of insurance companies to limit compensation payments by requiring injured and disabled workers to return to work, and many unions and other worker advocates try to build in flexibility and protection to allow a worker as much recovery time as necessary. A wide range of private rehabilitation services and hospital programs are involved in providing early recovery intervention and return to work support services.

¹⁸¹ National Academy of Social Insurance, Balancing Security and Opportunity: The Challenge of Disability Income Policy, Washington, D.C., 1996, p. 37.

So-called "Second Injury" Workers Compensation laws are in effect in all 50 states. These laws protect the employer, by limiting liability for on-the-job injuries caused or aggravated by an employee's disability. Prior to these laws being in place, many employers would not hire applicants with a disability for fear that a subsequent accident or injury would result in much higher claims and settlements. There are reports that claims to the Second Injury Fund are seldom made.

Long-Term Disability Insurance. Long-term disability insurance is a bit less common, with about 25% of the American work force covered by some type of insurance of this type. Insurance of this type at times provides a bridge between temporary or short-term benefits, and services provided around return to work. It also helps to supplement the usually modest level of earnings replacement that Social Security provides to middle- and upper-income workers¹⁸².

Social Security. Perhaps the biggest income support program that protects workers, which was addressed earlier in this section, but must be at least listed here.

Personal Assistance Services

Starting in 1979, Maine has had an extensive array of statewide Personal Assistance Services (PAS) for elders and adults with disabilities, many of whom have used these services to enable competitive employment. Personal assistance services are provided using consumer-directed, surrogate, and agency-based models. Maine uses Medicaid State Plan, Home- and community-based Waivers, State General fund, and consumer cost sharing to fund services.

PAS play an important role in enabling and supporting employment for people with disabilities. Maine PAS options, with one exception, allow employment supports, that is, assistance in getting ready for or being able to perform employment tasks, including having PAS provided in the workplace.

While there is no prohibition on providing PAS in order to prepare for or otherwise support employment, the PAS system is not equipped to significantly support employment. For the most part the current array of PAS supports, and the assessment procedures which help to identify what types of supports are needed, have been established without considering the needs of a person who is or will be working. There is a need to study current PAS offerings and additional policy options that Maine may take advantage of under new federal initiatives. PAS assessment tools need to be modified to identify what a person specifically needs in the home in order to prepare for work, as well as what PAS supports might be needed on the job site in order to successfully complete the job tasks.

The role that a better and more extensive PAS system can play in employment is the focus of additional efforts currently under way in the CHOICES project, and other efforts funded through the TWWIA law, discussed earlier, as well as the "Quality Choices" systems change grant and other initiatives related to community-based support services for individuals with disabilities.

¹⁸² National Academy of Social Insurance, p. 38.

MPower (formerly Kim D. Wallace) Adaptive Equipment Loan Program

The MPower Adaptive Equipment Loan Program provides long-term, low-interest financial loans for adaptive equipment and assistive technology. This equipment enables people with disabilities to live independently and improve their quality of life. With adaptive equipment/assistive technology, businesses and organization can have buildings and services that comply with the American with Disabilities Act. The program will lend up to \$100,000 to people, businesses or non-profit organizations to buy this equipment. Any Maine resident, community organization or business is eligible as long as the equipment assists one or more person with a disability to improve independence or quality of life or become more productive members of the community. The Loan Program's Board makes decisions regarding the award of all loans. In certain limited instances, smaller loans may not need Board approval.

The loan program is a \$6,500,000 fund co-administered by the Finance Authority of Maine and Alpha One, Maine's Center for Independent Living. As money is repaid, it is made available to other borrowers.

BRS/BDS Collaborative Effort

The Bureau of Rehabilitation Services and the Department of Behavioral and Developmental Services have been collaborating for several years to better coordinate services, policies and practices that support people with disabilities to find and maintain employment. This collaboration has greatly improved services for people with disabilities as transition from BRS services to BDS supports occurs.