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Maine Developmental
Disabilities Council

Evaluation & Governmental Accountability Report

to the

Joint Standing Committee
on
Health & Human Services

March 13, 2012

Maine Developmental Disabilities Council

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Maine Developmental Disabilities Council

Developmental Disabilities Assistance and Bill of Rights Act of 2000, PL 106-402

Summary

MISSION

The overall purpose of the DD Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote independence, productivity, integration, inclusion and self-determination through culturally competent programs.

The DD Act creates three programs:

State Council on Developmental Disabilities, the **Maine Developmental Disabilities Council**, focus on advocacy, capacity building, and systemic change, that among other things contribute to coordinated consumer and family-centered, family-directed efforts supporting community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families.

With respect to protection and advocacy systems, the DD Act restates the long-standing purpose to protect the legal and human rights of individuals with developmental disabilities. In Maine the agency charged with that mission is the **Disability Rights Center**.

University Centers for Excellence in Developmental Disabilities Education, Research and Service, were created to focus on continuing education as well as pre-service education, the provision of community services, the conduct of research, and the dissemination of information. In Maine this body is the **Center for Community Inclusion at the University of Maine**.

HISTORICAL CONTEXT

Originally authorized in 1963, the DD Act focused primarily on the establishment of University Affiliated Facilities (UAFs). These UAFs were charged with expanding the number of professionals to address the needs of persons with developmental disabilities.

The 1970 reauthorization established funding for Developmental Disabilities Councils to coordinate and integrate the provision of services for persons with developmental disabilities in the least restrictive environment.

In 1975, Congress created and authorized funding for Protection and Advocacy Systems in each state to ensure the safety and well being of individuals with developmental disabilities. The 1975 reauthorization also established and authorized funding for projects of national significance to address national needs.

In 2000 the DD Act was reauthorized and directs the current work of all three programs.

FINDINGS, PURPOSES, AND POLICY OF THE DD ACT

The legislation recognizes the basic precept that disability is a natural and normal part of the human experience. Individuals with developmental disabilities have the right to exert control and choice over their own lives and to fully participate in and contribute to their communities through full integration and inclusion in the mainstream.

The legislation clearly specifies that individuals with developmental disabilities often require lifelong community services, individualized supports, and other forms of assistance, and that these are most effective when provided in a coordinated manner within the community.

The legislation emphasizes that many service delivery systems and communities are not prepared to meet the impending needs of adults with developmental disabilities, whose primary caregivers are aging parents.

In addition, the legislation points out that in almost every state, individuals with developmental disabilities are waiting for appropriate services in their communities.

The legislation recognizes that there is an increasing need for a well-trained workforce that is able to provide services, supports, and other forms of direct assistance to individuals with developmental disabilities, living and working in the community and participating in all aspects of community life.

The goals of the Act include providing individuals with disabilities with the information, skills, opportunities and supports to live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights.

The stated purpose of the legislation is to ensure that programs, projects, and activities receiving assistance under the Act are carried out in a fashion consistent with the principles that individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination. This includes the following principles:

- Efforts undertaken to maintain or expand community-based living options should be monitored in order to determine that they are meeting quality assurance standards.
- Families of children with developmental disabilities need to have access to and use if safe and appropriate child care in the most integrated settings appropriate in order to enrich the participation of the children in community life.
- Individuals with developmental disabilities must have access to and use of public transportation in order to be independent and directly contribute to and participate in all facets of community life.
- Individuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings in order to enrich their participation in community life.

AREAS OF FOCUS

The DD Act specifies "emphasis areas" on which the State Developmental Disability Councils are to focus: quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, and formal and informal community supports that affect the quality of life.

The legislation offers specific definitions of several terms that set the tone of the legislation and shape the scope and direction of Council activities.

"Individualized supports" enable an individual with a developmental disability to exercise self-determination, as well as be independent, productive and integrated and included in the community.

"Quality assurance" results in systems that monitor services, and train in leadership in self-advocacy and self-determination for individuals with developmental disabilities, their families, and their guardians.

"Self-determination" leads individuals with developmental disabilities to have —

- The ability and opportunity to communicate and make personal decisions.
- The ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance received.

- The authority to control resources to obtain needed services, supports, and other assistance.
- Opportunities to participate in and contribute to a community.
- Support, including financial support, to advocate for one's self and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

STATE DD COUNCILS

State Plan:

Each state DD Council must submit a data driven strategic plan every five years, and update as needed. The plan must describe the results of a comprehensive review and analysis, which includes:

- A description of programs relating to areas of emphasis
- A description of the extent to which agencies operating programs pursue interagency initiatives.
- An analysis of the extent to which community services and opportunities related to the areas of emphasis contribute to community life.

The plan must focus DD Council efforts around areas of emphasis that:

- Are derived from unmet needs
- Include a goal for each year of the grant to establish or strengthen a program for direct funding of a state self-advocacy organization led by individuals with developmental disabilities.
- Are consistent with the indicators of progress and the strategies used.

Not less than 70 percent of funds under the subtitle must be expanded for activities related to the goals specified in the state plan.

The plan must provide assurances that the Council will participate in state quality assurance systems affecting individuals with developmental disabilities.

The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council.

The plan shall also provide assurances that there will be reasonable state financial participation in the cost of carrying out the plan. The DD Act expresses specific formulas for part calculating state financial participation.

Membership:

Not less than 60 percent of Council membership must consist of individuals with developmental disabilities or immediate relatives or guardians of adults with developmental disabilities who cannot advocate for themselves. Membership shall be appointed by the Governor from among the residents of the state, with recommendations made by the Council.

Council Responsibilities and State Plan Implementation:

Council responsibilities include the implementation of the state plan and an examination of the goals and outcomes, unmet needs, and customer satisfaction. A staff to the Council shall be hired to assist with these responsibilities.

Activities that meet the purpose of the act include:

- Outreach
- Training
- Technical Assistance
- Supporting and Educating Communities
- Interagency Collaboration
- Coordination with related Councils and programs
- Barrier elimination, system design and redesign
- Coalition development and citizen participation, including training in self-advocacy, education of policymakers, and citizen leadership skills,
- Demonstration of new approaches to services and supports
- Other activities that achieve the purposes of the subtitle.

Reports:

The Council must annually prepare and transmit a report to the Secretary containing information about the progress of the Council in achieving its goals, including:

- A description of strategies that contributed to achieving the goals.
- The extent to which the goals were not achieved and the factors impeding the achievement.
- Separate information on the self-advocacy goal.
- Information on consumer satisfaction.
- A description of the adequacy of services provided in ICF/MRs.
- A description of the adequacy of services provided which home and community-based waivers.

Funding:

The federal government allocates funding for DD Councils based on a funding formula. The state must also provide the Council with financial support, which may be provided in-kind.

State Support:

The Governor shall designate a State agency to provide support as required by the Council and their particular status within the state system. An agency will be designated only after an independent assessment has been made that the chosen agency will not interfere with the budget, personnel, priorities, or other action of the Council, and the ability of the Council to serve as an independent advocate for individuals with developmental disabilities.

Developmental Disabilities Assistance

And

Bill of Rights Act of 2000

PL 106-402

October 20, 2000

Administration on
Developmental Disabilities

Public Law 106-402-OCT. 30, 2001

One Hundred Sixth Congress of the United States of America

An Act

To improve service systems for individuals with developmental disabilities, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE- This Act may be cited as the `Developmental Disabilities Assistance and Bill of Rights Act of 2000'.

(b) TABLE OF CONTENTS- The table of contents of this Act is as follows:

TITLE I--PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Subtitle A--General Provisions

Subtitle B--Federal Assistance to State Councils on Developmental Disabilities

TITLE IV--REPEAL

TITLE I--PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Subtitle A--General Provisions

SEC. 101. FINDINGS, PURPOSES, AND POLICY.

(a) **FINDINGS**- Congress finds that--

(1) disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society;

(2) in 1999, there were between 3,200,000 and 4,500,000 individuals with developmental disabilities in the United States, and recent studies indicate that individuals with developmental disabilities comprise between 1.2 and 1.65 percent of the United States population;

(3) individuals whose disabilities occur during their developmental period frequently have severe disabilities that are likely to continue indefinitely;

(4) individuals with developmental disabilities often encounter discrimination in the provision of critical services, such as services in the areas of emphasis (as defined in section 102);

(5) individuals with developmental disabilities are at greater risk than the general population of abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights;

(6) a substantial portion of individuals with developmental disabilities and their families do not have access to appropriate support and services, including access to assistive technology, from generic and specialized service systems, and remain unserved or underserved;

(7) individuals with developmental disabilities often require lifelong community services, individualized supports, and other forms of assistance, that are most effective when provided in a coordinated manner;

(8) there is a need to ensure that services, supports, and other assistance are provided in a culturally competent manner, that ensures that individuals from racial and ethnic minority backgrounds are fully included in all activities provided under this title;

(9) family members, friends, and members of the community can play an important role in enhancing the lives of individuals with developmental disabilities, especially when the family members, friends, and community members are provided with the necessary community services, individualized supports, and other forms of assistance;

(10) current research indicates that 88 percent of individuals with developmental disabilities live with their families or in their own households;

(11) many service delivery systems and communities are not prepared to meet the impending needs of the 479,862 adults with developmental disabilities who are living at home with parents who are 60 years old or older and who serve as the primary caregivers of the adults;

(12) in almost every State, individuals with developmental disabilities are waiting for appropriate services in their communities, in the areas of emphasis;

(13) the public needs to be made more aware of the capabilities and competencies of individuals with developmental disabilities, particularly in cases in which the individuals are provided with necessary services, supports, and other assistance;

(14) as increasing numbers of individuals with developmental disabilities are living, learning, working, and participating in all aspects of community life, there is an increasing need for a well trained workforce that is able to provide the services, supports, and other forms of direct assistance required to enable the individuals to carry out those activities;

(15) there needs to be greater effort to recruit individuals from minority backgrounds into professions serving individuals with developmental disabilities and their families;

(16) the goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to--

(A) make informed choices and decisions about their lives;

(B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;

(C) pursue meaningful and productive lives;

(D) contribute to their families, communities, and States, and the Nation;

(E) have interdependent friendships and relationships with other persons;

(F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and

(G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual; and

(17) as the Nation, States, and communities maintain and expand community living options for individuals with developmental disabilities, there is a need to evaluate the access to those options by individuals with developmental disabilities and the effects of those options on individuals with developmental disabilities.

(b) **PURPOSE-** The purpose of this title is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title, including specifically--

(1) State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities that--

(A) are consistent with the purpose described in this subsection and the policy described in subsection (c); and

(B) contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families;

(2) protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities;

(3) University Centers for Excellence in Developmental Disabilities Education, Research, and Service--

(A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this title;

(B) to provide community services--

(i) that provide training and technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community; and

(ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities;

(C) to conduct research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families; and

(D) to disseminate information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances; and

(4) funding for--

(A) national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities;

(B) technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in subsection (c); and

(C) other nationally significant activities.

(c) **POLICY**- It is the policy of the United States that all programs, projects, and activities receiving assistance under this title shall be carried out in a manner consistent with the principles that--

(1) individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life, but often require the provision of community services, individualized supports, and other forms of assistance;

(2) individuals with developmental disabilities and their families have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals;

(3) individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families;

(4) services, supports, and other assistance should be provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences;

(5) specific efforts must be made to ensure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families;

(6) recruitment efforts in disciplines related to developmental disabilities relating to pre-service training, community training, practice, administration, and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the disciplines in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population;

(7) with education and support, communities can be accessible to and responsive to the needs of individuals with developmental disabilities and their families and are enriched by full and active participation in community activities, and contributions, by individuals with developmental disabilities and their families;

(8) individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation;

(9) efforts undertaken to maintain or expand community-based living options for individuals with disabilities should be monitored in order to determine and report to appropriate individuals and entities the extent of access by individuals with developmental disabilities to those options and the extent of compliance by entities providing those options with quality assurance standards;

(10) families of children with developmental disabilities need to have access to and use of safe and appropriate child care and before-school and after-school programs, in the most integrated settings, in order to enrich the participation of the children in community life;

(11) individuals with developmental disabilities need to have access to and use of public transportation, in order to be independent and directly contribute to and participate in all facets of community life; and

(12) individuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life.

SEC. 102. DEFINITIONS.

In this title:

(1) **AMERICAN INDIAN CONSORTIUM**- The term `American Indian Consortium' means any confederation of 2 or more recognized American Indian tribes, created through the official action of each participating tribe, that has a combined total resident population of 150,000 enrolled tribal members and a contiguous territory of Indian lands in 2 or more States.

(2) **AREAS OF EMPHASIS**- The term `areas of emphasis' means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life.

(3) **ASSISTIVE TECHNOLOGY DEVICE**- The term `assistive technology device' means any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with developmental disabilities.

(4) **ASSISTIVE TECHNOLOGY SERVICE**- The term `assistive technology service' means any service that directly assists an individual with a developmental disability in the selection, acquisition, or use of an assistive technology device. Such term includes--

(A) conducting an evaluation of the needs of an individual with a developmental disability, including a functional evaluation of the individual in the individual's customary environment;

(B) purchasing, leasing, or otherwise providing for the acquisition of an assistive technology device by an individual with a developmental disability;

(C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing or replacing an assistive technology device;

(D) coordinating and using another therapy, intervention, or service with an assistive technology device, such as a therapy, intervention, or service associated with an education or rehabilitation plan or program;

(E) providing training or technical assistance for an individual with a developmental disability, or, where appropriate, a family member, guardian, advocate, or authorized representative of an individual with a developmental disability; and

(F) providing training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of, an individual with developmental disabilities.

(5) **CENTER-** The term `Center' means a University Center for Excellence in Developmental Disabilities Education, Research, and Service established under subtitle D.

(6) **CHILD CARE-RELATED ACTIVITIES**- The term `child care-related activities' means advocacy, capacity building, and systemic change activities that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities.

(7) **CULTURALLY COMPETENT**- The term `culturally competent', used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

(8) **DEVELOPMENTAL DISABILITY-**

(A) **IN GENERAL**- The term `developmental disability' means a severe, chronic disability of an individual that--

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(B) **INFANTS AND YOUNG CHILDREN**- An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

(9) **EARLY INTERVENTION ACTIVITIES**- The term `early intervention activities' means advocacy, capacity building, and systemic change activities provided to individuals described in paragraph (8)(B) and their families to enhance--

(A) the development of the individuals to maximize their potential; and

(B) the capacity of families to meet the special needs of the individuals.

(10) **EDUCATION ACTIVITIES**- The term `education activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life.

(11) **EMPLOYMENT-RELATED ACTIVITIES**- The term `employment-related activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

(12) **FAMILY SUPPORT SERVICES**-

> (A) **IN GENERAL**- The term `family support services' means services, supports, and other assistance, provided to families with members who have developmental disabilities, that are designed to--
>
> > (i) strengthen the family's role as primary caregiver;
> >
> > (ii) prevent inappropriate out-of-the-home placement of the members and maintain family unity; and
> >
> > (iii) reunite families with members who have been placed out of the home whenever possible.
>
> (B) **SPECIFIC SERVICES**- Such term includes respite care, provision of rehabilitation technology and assistive technology, personal assistance services, parent training and counseling, support for families headed by aging caregivers, vehicular and home modifications, and assistance with extraordinary expenses, associated with the needs of individuals with developmental disabilities.

(13) **HEALTH-RELATED ACTIVITIES**- The term `health-related activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities.

(14) **HOUSING-RELATED ACTIVITIES**- The term `housing-related activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

(15) **INCLUSION**- The term `inclusion', used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to--

> (A) have friendships and relationships with individuals and families of their own choice;
>
> (B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;

(C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and

(D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

(16) **INDIVIDUALIZED SUPPORTS**- The term `individualized supports' means supports that--

(A) enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life;

(B) are designed to--

(i) enable such individual to control such individual's environment, permitting the most independent life possible;

(ii) prevent placement into a more restrictive living arrangement than is necessary; and

(iii) enable such individual to live, learn, work, and enjoy life in the community; and

(C) include--

(i) early intervention services;

(ii) respite care;

(iii) personal assistance services;

(iv) family support services;

(v) supported employment services;

(vi) support services for families headed by aging caregivers of individuals with developmental disabilities; and

(vii) provision of rehabilitation technology and assistive technology, and assistive technology services.

(17) **INTEGRATION**- The term `integration', used with respect to individuals with developmental disabilities, means exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

(18) **NOT-FOR-PROFIT**- The term `not-for-profit', used with respect to an agency, institution, or organization, means an agency, institution, or organization that is owned or operated by 1 or more corporations or associations, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

(19) **PERSONAL ASSISTANCE SERVICES**- The term `personal assistance services' means a range of services, provided by 1 or more individuals, designed to assist an individual with a disability to perform daily activities, including activities on or off a job that such individual would typically perform if such individual did not have a disability. Such services shall be designed to increase such individual's control in life and ability to perform everyday activities, including activities on or off a job.

(20) **PREVENTION ACTIVITIES**- The term `prevention activities' means activities that address the causes of developmental disabilities and the exacerbation of functional limitation, such as activities that--

(A) eliminate or reduce the factors that cause or predispose individuals to developmental disabilities or that increase the prevalence of developmental disabilities;

(B) increase the early identification of problems to eliminate circumstances that create or increase functional limitations; and

(C) mitigate against the effects of developmental disabilities throughout the lifespan of an individual.

(21) **PRODUCTIVITY**- The term `productivity' means--

(A) engagement in income-producing work that is measured by increased income, improved employment status, or job advancement; or

(B) engagement in work that contributes to a household or community.

(22) **PROTECTION AND ADVOCACY SYSTEM**- The term `protection and advocacy system' means a protection and advocacy system established in accordance with section 143.

(23) **QUALITY ASSURANCE ACTIVITIES**- The term `quality assurance activities' means advocacy, capacity building, and systemic change activities that result in improved consumer- and family-centered quality assurance and that result in systems of quality assurance and consumer protection that--

(A) include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual--

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion;

(B) include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals--

(i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and

(ii) will not be subject to the inappropriate use of restraints or seclusion; or

(C) include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.

(24) **RECREATION-RELATED ACTIVITIES**- The term `recreation-related activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of recreational, leisure, and social activities, in their communities.

(25) **REHABILITATION TECHNOLOGY**- The term `rehabilitation technology' means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, individuals with developmental disabilities in areas that include education, rehabilitation, employment, transportation, independent living, and recreation. Such term includes rehabilitation engineering, and the provision of assistive technology devices and assistive technology services.

(26) **SECRETARY**- The term `Secretary' means the Secretary of Health and Human Services.

(27) **SELF-DETERMINATION ACTIVITIES**- The term `self-determination activities' means activities that result in individuals with developmental disabilities, with appropriate assistance, having-

(A) the ability and opportunity to communicate and make personal decisions;

(B) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;

(C) the authority to control resources to obtain needed services, supports, and other assistance;

(D) opportunities to participate in, and contribute to, their communities; and

(E) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

(28) **STATE**- The term `State', except as otherwise provided, includes, in addition to each of the several States of the United States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

(29) **STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**- The term `State Council on Developmental Disabilities' means a Council established under section 125.

(30) **SUPPORTED EMPLOYMENT SERVICES**- The term `supported employment services' means services that enable individuals with developmental disabilities to perform competitive work in integrated work settings, in the case of individuals with developmental disabilities--

(A)(i) for whom competitive employment has not traditionally occurred; or

(ii) for whom competitive employment has been interrupted or intermittent as a result of significant disabilities; and

(B) who, because of the nature and severity of their disabilities, need intensive supported employment services or extended services in order to perform such work.

(31) **TRANSPORTATION-RELATED ACTIVITIES**- The term `transportation-related activities' means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

(32) **UNSERVED AND UNDERSERVED**- The term `unserved and underserved' includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life.

SEC. 103. RECORDS AND AUDITS.

(a) **RECORDS**- Each recipient of assistance under this title shall keep such records as the Secretary shall prescribe, including--

(1) records that fully disclose--

(A) the amount and disposition by such recipient of the assistance;

(B) the total cost of the project or undertaking in connection with which such assistance is given or used; and

(C) the amount of that portion of the cost of the project or undertaking that is supplied by other sources; and

(2) such other records as will facilitate an effective audit.

(b) **ACCESS**- The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipients of assistance under this title that are pertinent to such assistance.

SEC. 104. RESPONSIBILITIES OF THE SECRETARY.

(a) **PROGRAM ACCOUNTABILITY-**

(1) **IN GENERAL-** In order to monitor entities that received funds under this Act to carry out activities under subtitles B, C, and D and determine the extent to which the entities have been responsive to the purpose of this title and have taken actions consistent with the policy described in section 101(c), the Secretary shall develop and implement an accountability process as described in this subsection, with respect to activities conducted after October 1, 2001.

(2) **AREAS OF EMPHASIS**- The Secretary shall develop a process for identifying and reporting (pursuant to section 105) on progress achieved through advocacy, capacity building, and systemic change activities, undertaken by the entities described in paragraph (1), that resulted in individuals with developmental disabilities and their families participating in the design of and having access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life. Specifically, the Secretary shall develop a process for identifying and reporting on progress achieved, through advocacy, capacity building, and systemic change activities, by the entities in the areas of emphasis.

(3) **INDICATORS OF PROGRESS**-

(A) **IN GENERAL**- In identifying progress made by the entities described in paragraph (1) in the areas of emphasis, the Secretary, in consultation with the

Commissioner of the Administration on Developmental Disabilities and the entities, shall develop indicators for each area of emphasis.

(B) **PROPOSED INDICATORS**- Not later than 180 days after the date of enactment of this Act, the Secretary shall develop and publish in the Federal Register for public comment proposed indicators of progress for monitoring how entities described in paragraph (1) have addressed the areas of emphasis described in paragraph (2) in a manner that is responsive to the purpose of this title and consistent with the policy described in section 101(c).

(C) **FINAL INDICATORS**- Not later than October 1, 2001, the Secretary shall revise the proposed indicators of progress, to the extent necessary based on public comment, and publish final indicators of progress in the Federal Register.

(D) **SPECIFIC MEASURES**- At a minimum, the indicators of progress shall be used to describe and measure--

(i) the satisfaction of individuals with developmental disabilities with the advocacy, capacity building, and systemic change activities provided under subtitles B, C, and D;

(ii) the extent to which the advocacy, capacity building, and systemic change activities provided through subtitles B, C, and D result in improvements in--

(I) the ability of individuals with developmental disabilities to make choices and exert control over the type, intensity, and timing of services, supports, and assistance that the individuals have used;

(II) the ability of individuals with developmental disabilities to participate in the full range of community life with persons of the individuals' choice; and

(III) the ability of individuals with developmental disabilities to access services, supports, and assistance in a manner that ensures that such an individual is free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restraints and seclusion; and

(iii) the extent to which the entities described in paragraph (1) collaborate with each other to achieve the purpose of this title and the policy described in section 101(c).

(4) **TIME LINE FOR COMPLIANCE WITH INDICATORS OF PROGRESS**- The Secretary shall require entities described in paragraph (1) to meet the indicators of progress described in paragraph (3). For fiscal year 2002 and each year thereafter, the Secretary shall apply the indicators in monitoring entities described in paragraph (1), with respect to activities conducted after October 1, 2001.

(b) **TIME LINE FOR REGULATIONS**- Except as otherwise expressly provided in this title, the Secretary, not later than 1 year after the date of enactment of this Act, shall promulgate such regulations as may be required for the implementation of this title.

(c) **INTERAGENCY COMMITTEE**-

(1) **IN GENERAL**- The Secretary shall maintain the interagency committee authorized in section 108 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C.

6007) as in effect on the day before the date of enactment of this Act, except as otherwise provided in this subsection.

(2) **COMPOSITION-** The interagency committee shall be composed of representatives of--

(A) the Administration on Developmental Disabilities, the Administration on Children, Youth, and Families, the Administration on Aging, and the Health Resources and Services Administration, of the Department of Health and Human Services; and

(B) such other Federal departments and agencies as the Secretary of Health and Human Services considers to be appropriate.

(3) **DUTIES**- Such interagency committee shall meet regularly to coordinate and plan activities conducted by Federal departments and agencies for individuals with developmental disabilities.

(4) **MEETINGS**- Each meeting of the interagency committee (except for any meetings of any subcommittees of the committee) shall be open to the public. Notice of each meeting, and a statement of the agenda for the meeting, shall be published in the Federal Register not later than 14 days before the date on which the meeting is to occur.

SEC. 105. REPORTS OF THE SECRETARY.

At least once every 2 years, the Secretary, using information submitted in the reports and information required under subtitles B, C, D, and E, shall prepare and submit to the President, Congress, and the National Council on Disability, a report that describes the goals and outcomes of programs supported under subtitles B, C, D, and E. In preparing the report, the Secretary shall provide--

(1) meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded under subtitles B, C, D, and E, respectively--

(A) have undertaken coordinated activities with each other;

(B) have enhanced the ability of individuals with developmental disabilities and their families to participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life;

(C) have brought about advocacy, capacity building, and systemic change activities (including policy reform), and other actions on behalf of individuals with developmental disabilities and their families, including individuals who are traditionally unserved or underserved, particularly individuals who are members of ethnic and racial minority groups and individuals from underserved geographic areas; and

(D) have brought about advocacy, capacity building, and systemic change activities that affect individuals with disabilities other than individuals with developmental disabilities;

(2) information on the extent to which programs authorized under this title have addressed--

(A) protecting individuals with developmental disabilities from abuse, neglect, sexual and financial exploitation, and violations of legal and human rights, so that those individuals are at no greater risk of harm than other persons in the general population; and

(B) reports of deaths of and serious injuries to individuals with developmental disabilities; and

(3) a summary of any incidents of noncompliance of the programs authorized under this title with the provisions of this title, and corrections made or actions taken to obtain compliance.

SEC. 106. STATE CONTROL OF OPERATIONS.

Except as otherwise specifically provided, nothing in this title shall be construed as conferring on any Federal officer or employee the right to exercise any supervision or control over the administration, personnel, maintenance, or operation of any programs, services, and supports for individuals with developmental disabilities with respect to which any funds have been or may be expended under this title.

SEC. 107. EMPLOYMENT OF INDIVIDUALS WITH DISABILITIES.

As a condition of providing assistance under this title, the Secretary shall require that each recipient of such assistance take affirmative action to employ and advance in employment qualified individuals with disabilities on the same terms and conditions required with respect to the employment of such individuals under the provisions of title V of the Rehabilitation Act of 1973 (29 U.S.C. 791 et seq.) and the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), that govern employment.

SEC. 108. CONSTRUCTION.

Nothing in this title shall be construed to preclude an entity funded under this title from engaging in advocacy, capacity building, and systemic change activities for individuals with developmental disabilities that may also have a positive impact on individuals with other disabilities.

SEC. 109. RIGHTS OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES.

(a) **IN GENERAL**- Congress makes the following findings respecting the rights of individuals with developmental disabilities:

(1) Individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities, consistent with section 101(c).

(2) The treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual's personal liberty.

(3) The Federal Government and the States both have an obligation to ensure that public funds are provided only to institutional programs, residential programs, and other community programs, including educational programs in which individuals with developmental disabilities participate, that--

(A) provide treatment, services, and habilitation that are appropriate to the needs of such individuals; and

(B) meet minimum standards relating to--

(i) provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;

(ii) provision to such individuals of appropriate and sufficient medical and dental services;

(iii) prohibition of the use of physical restraint and seclusion for such an individual unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibition of the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program;

(iv) prohibition of the excessive use of chemical restraints on such individuals and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals; and

(v) provision for close relatives or guardians of such individuals to visit the individuals without prior notice.

(4) All programs for individuals with developmental disabilities should meet standards--

(A) that are designed to assure the most favorable possible outcome for those served; and

(B)(i) in the case of residential programs serving individuals in need of comprehensive health-related, habilitative, assistive technology or rehabilitative services, that are at least equivalent to those standards applicable to intermediate care facilities for the mentally retarded, promulgated in regulations of the Secretary on June 3, 1988, as appropriate, taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

(ii) in the case of other residential programs for individuals with developmental disabilities, that assure that--

(I) care is appropriate to the needs of the individuals being served by such programs;

(II) the individuals admitted to facilities of such programs are individuals whose needs can be met through services provided by such facilities; and

(III) the facilities of such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

(iii) in the case of nonresidential programs, that assure that the care provided by such programs is appropriate to the individuals served by the programs.

(b) **CLARIFICATION**- The rights of individuals with developmental disabilities described in findings made in this section shall be considered to be in addition to any constitutional or other rights otherwise afforded to all individuals.

Subtitle B--Federal Assistance to State Councils on Developmental Disabilities

SEC. 121. PURPOSE.

The purpose of this subtitle is to provide for allotments to support State Councils on Developmental Disabilities (referred to individually in this subtitle as a `Council') in each State to--

(1) engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose described in section 101(b) and the policy described in section 101(c); and

(2) contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life.

SEC. 122. STATE ALLOTMENTS.

(a) **ALLOTMENTS**-

(1) **IN GENERAL**-

(A) **AUTHORITY**- For each fiscal year, the Secretary shall, in accordance with regulations and this paragraph, allot the sums appropriated for such year under section 129 among the States on the basis of--

(i) the population;

(ii) the extent of need for services for individuals with developmental disabilities; and

(iii) the financial need,

of the respective States.

(B) **USE OF FUNDS**- Sums allotted to the States under this section shall be used to pay for the Federal share of the cost of carrying out projects in accordance with State plans approved under section 124 for the provision under such plans of services for individuals with developmental disabilities.

(2) **ADJUSTMENTS**- The Secretary may make adjustments in the amounts of State allotments based on clauses (i), (ii), and (iii) of paragraph (1)(A) not more often than annually. The Secretary shall notify each State of any adjustment made under this paragraph and the percentage of the total sums appropriated under section 129 that the adjusted allotment represents not later than 6 months before the beginning of the fiscal year in which such adjustment is to take effect.

(3) **MINIMUM ALLOTMENT FOR APPROPRIATIONS LESS THAN OR EQUAL TO $70,000,000**-

(A) **IN GENERAL**- Except as provided in paragraph (4), for any fiscal year the allotment under this section--

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than $210,000; and

(ii) to any State not described in clause (i) may not be less than $400,000.

(B) **REDUCTION OF ALLOTMENT**- Notwithstanding subparagraph (A), if the aggregate of the amounts to be allotted to the States pursuant to subparagraph (A) for any fiscal year exceeds the total amount appropriated under section 129 for such fiscal year, the amount to be allotted to each State for such fiscal year shall be proportionately reduced.

(4) **MINIMUM ALLOTMENT FOR APPROPRIATIONS IN EXCESS OF $70,000,000-**

(A) **IN GENERAL**- In any case in which the total amount appropriated under section 129 for a fiscal year is more than $70,000,000, the allotment under this section for such fiscal year--

(i) to each of American Samoa, Guam, the United States Virgin Islands, or the Commonwealth of the Northern Mariana Islands may not be less than $220,000; and

(ii) to any State not described in clause (i) may not be less than $450,000.

(B) **REDUCTION OF ALLOTMENT**- The requirements of paragraph (3)(B) shall apply with respect to amounts to be allotted to States under subparagraph (A), in the same manner and to the same extent as such requirements apply with respect to amounts to be allotted to States under paragraph (3)(A).

(5) **STATE SUPPORTS, SERVICES, AND OTHER ACTIVITIES**- In determining, for purposes of paragraph (1)(A)(ii), the extent of need in any State for services for individuals with developmental disabilities, the Secretary shall take into account the scope and extent of the services, supports, and assistance described, pursuant to section 124(c)(3)(A), in the State plan of the State.

(6) **INCREASE IN ALLOTMENTS**- In any year in which the total amount appropriated under section 129 for a fiscal year exceeds the total amount appropriated under such section (or a corresponding provision) for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 100(c)(1) of the Rehabilitation Act of 1973 (29 U.S.C. 720(c)(1)) (if the percentage change indicates an increase), the Secretary shall increase each of the minimum allotments described in paragraphs (3) and (4). The Secretary shall increase each minimum allotment by an amount that bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph (or a corresponding provision) for prior fiscal years) as the amount that is equal to the difference between--

(A) the total amount appropriated under section 129 for the fiscal year for which the increase in the minimum allotment is being made; minus

(B) the total amount appropriated under section 129 (or a corresponding provision) for the immediately preceding fiscal year,

bears to the total amount appropriated under section 129 (or a corresponding provision) for such preceding fiscal year.

(b) **UNOBLIGATED FUNDS**- Any amount paid to a State for a fiscal year and remaining unobligated at the end of such year shall remain available to such State for the next fiscal year for the purposes for which such amount was paid.

(c) **OBLIGATION OF FUNDS**- For the purposes of this subtitle, State Interagency Agreements are considered valid obligations for the purpose of obligating Federal funds allotted to the State under this subtitle.

(d) **COOPERATIVE EFFORTS BETWEEN STATES**- If a State plan approved in accordance with section 124 provides for cooperative or joint effort between or among States or agencies, public or private, in more than 1 State, portions of funds allotted to 1 or more States described in this subsection may be combined in accordance with the agreements between the States or agencies involved.

(e) **REALLOTMENTS**-

(1) **IN GENERAL**- If the Secretary determines that an amount of an allotment to a State for a period (of a fiscal year or longer) will not be required by the State during the period for the purpose for which the allotment was made, the Secretary may reallot the amount.

(2) **TIMING**- The Secretary may make such a reallotment from time to time, on such date as the Secretary may fix, but not earlier than 30 days after the Secretary has published notice of the intention of the Secretary to make the reallotment in the Federal Register.

(3) **AMOUNTS**- The Secretary shall reallot the amount to other States with respect to which the Secretary has not made that determination. The Secretary shall reallot the amount in proportion to the original allotments of the other States for such fiscal year, but shall reduce such proportionate amount for any of the other States to the extent the proportionate amount exceeds the sum that the Secretary estimates the State needs and will be able to use during such period.

(4) **REALLOTMENT OF REDUCTIONS**- The Secretary shall similarly reallot the total of the reductions among the States whose proportionate amounts were not so reduced.

(5) **TREATMENT**- Any amount reallotted to a State under this subsection for a fiscal year shall be deemed to be a part of the allotment of the State under subsection (a) for such fiscal year.

SEC. 123. PAYMENTS TO THE STATES FOR PLANNING, ADMINISTRATION, AND SERVICES.

(a) **STATE PLAN EXPENDITURES**- From each State's allotments for a fiscal year under section 122, the Secretary shall pay to the State the Federal share of the cost, other than the cost for construction, incurred during such year for activities carried out under the State plan approved under section 124. The Secretary shall make such payments from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend for the cost under the State plan. The Secretary shall make such adjustments as may be necessary to the payments on account of previously made underpayments or overpayments under this section.

(b) **DESIGNATED STATE AGENCY EXPENDITURES**- The Secretary may make payments to a State for the portion described in section 124(c)(5)(B)(vi) in advance or by way of reimbursement, and in such installments as the Secretary may determine.

SEC. 124. STATE PLAN.

(a) **IN GENERAL**- Any State desiring to receive assistance under this subtitle shall submit to the Secretary, and obtain approval of, a 5-year strategic State plan under this section.

(b) **PLANNING CYCLE**- The plan described in subsection (a) shall be updated as appropriate during the 5-year period.

(c) **STATE PLAN REQUIREMENTS**- In order to be approved by the Secretary under this section, a State plan shall meet each of the following requirements:

(1) **STATE COUNCIL**- The plan shall provide for the establishment and maintenance of a Council in accordance with section 125 and describe the membership of such Council.

(2) **DESIGNATED STATE AGENCY**- The plan shall identify the agency or office within the State designated to support the Council in accordance with this section and section 125(d) (referred to in this subtitle as a `designated State agency').

(3) **COMPREHENSIVE REVIEW AND ANALYSIS**- The plan shall describe the results of a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, and the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State. The results of the comprehensive review and analysis shall include--

(A) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including--

(i) medical assistance, maternal and child health care, services for children with special health care needs, children's mental health services, comprehensive health and mental health services, and institutional care options;

(ii) job training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and

(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;

(C) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly--

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) a description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on each independent review (pursuant to section 1902(a)(30)(C) of the Social Security Act (42 U.S.C. 1396a(a)(30)(C))) of an Intermediate Care Facility (Mental Retardation) within the State, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))) receive;

(D) a description of how entities funded under subtitles C and D, through interagency agreements or other mechanisms, collaborated with the entity funded under this subtitle in the State, each other, and other entities to contribute to the achievement of the purpose of this subtitle; and

(E) the rationale for the goals related to advocacy, capacity building, and systemic change to be undertaken by the Council to contribute to the achievement of the purpose of this subtitle.

(4) **PLAN GOALS**- The plan shall focus on Council efforts to bring about the purpose of this subtitle, by--

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that--

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to--

(I) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;

(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and

(B) for each year of the grant, describing--

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 104(a)(3);

(ii) the strategies to be used in achieving each goal; and

(iii) the method to be used to determine if each goal has been achieved.

(5) **ASSURANCES**-

(A) **IN GENERAL**- The plan shall contain or be supported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) **USE OF FUNDS**- With respect to the funds paid to the State under section 122, the plan shall provide assurances that--

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political subdivisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds that would otherwise be made available for the purposes for which the funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) at the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1/2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or $50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and

(vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that--

(I) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

(C) **STATE FINANCIAL PARTICIPATION**- The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) **CONFLICT OF INTEREST**- The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

(E) **URBAN AND RURAL POVERTY AREAS**- The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.

(F) **PROGRAM ACCESSIBILITY STANDARDS**- The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 508 of the Rehabilitation Act of 1973 (29 U.S.C. 794d), and the Fair Housing Act (42 U.S.C. 3601 et seq.).

(G) **INDIVIDUALIZED SERVICES**- The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) **HUMAN RIGHTS**- The plan shall provide assurances that the human rights of the individuals with developmental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this subtitle will be protected consistent with section 109 (relating to rights of individuals with developmental disabilities).

(I) **MINORITY PARTICIPATION**- The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this subtitle is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) **EMPLOYEE PROTECTIONS**- The plan shall provide assurances that fair and equitable arrangements (as determined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) **STAFF ASSIGNMENTS**- The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) **NONINTERFERENCE**- The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3).

(M) **STATE QUALITY ASSURANCE**- The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) **OTHER ASSURANCES**- The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this subtitle.

(d) **PUBLIC INPUT AND REVIEW, SUBMISSION, AND APPROVAL**-

(1) **PUBLIC INPUT AND REVIEW**- The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comments.

(2) **CONSULTATION WITH THE DESIGNATED STATE AGENCY**- Before the plan is submitted to the Secretary, the Council shall consult with the designated State agency to ensure that the State plan is consistent with State law and to obtain appropriate State plan assurances.

(3) **PLAN APPROVAL**- The Secretary shall approve any State plan and, as appropriate, amendments of such plan that comply with the provisions of subsections (a), (b), and (c) and this subsection. The Secretary may take final action to disapprove a State plan after providing reasonable notice and an opportunity for a hearing to the State.

SEC. 125. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES AND DESIGNATED STATE AGENCIES.

(a) **IN GENERAL**- Each State that receives assistance under this subtitle shall establish and maintain a Council to undertake advocacy, capacity building, and systemic change activities (consistent with subsections (b) and (c) of section 101) that contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this subtitle. The Council shall have the authority to fulfill the responsibilities described in subsection (c).

(b) **COUNCIL MEMBERSHIP**-

(1) **COUNCIL APPOINTMENTS**-

(A) **IN GENERAL**- The members of the Council of a State shall be appointed by the Governor of the State from among the residents of that State.

(B) **RECOMMENDATIONS**- The Governor shall select members of the Council, at the discretion of the Governor, after soliciting recommendations from organizations representing a broad range of individuals with developmental disabilities and individuals interested in individuals with developmental disabilities, including the non-State agency members of the Council. The Council may, at the initiative of the Council, or on the request of the Governor, coordinate Council and public input to the Governor regarding all recommendations.

(C) **REPRESENTATION**- The membership of the Council shall be geographically representative of the State and reflect the diversity of the State with respect to race and ethnicity.

(2) **MEMBERSHIP ROTATION**- The Governor shall make appropriate provisions to rotate the membership of the Council. Such provisions shall allow members to continue to serve on the Council until such members' successors are appointed. The Council shall notify the Governor regarding membership requirements of the Council, and shall notify the Governor when vacancies on the Council remain unfilled for a significant period of time.

(3) **REPRESENTATION OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**- Not less than 60 percent of the membership of each Council shall consist of individuals who are--

(A)(i) individuals with developmental disabilities;

(ii) parents or guardians of children with developmental disabilities; or

(iii) immediate relatives or guardians of adults with mentally impairing developmental disabilities who cannot advocate for themselves; and

(B) not employees of a State agency that receives funds or provides services under this subtitle, and who are not managing employees (as defined in section 1126(b) of the Social Security Act (42 U.S.C. 1320a-5(b)) of any other entity that receives funds or provides services under this subtitle.

(4) **REPRESENTATION OF AGENCIES AND ORGANIZATIONS**-

(A) **IN GENERAL**- Each Council shall include--

(i) representatives of relevant State entities, including--

(I) State entities that administer funds provided under Federal laws related to individuals with disabilities, including the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.), the Older Americans Act of 1965 (42 U.S.C. 3001 et seq.), and titles V and XIX of the Social Security Act (42 U.S.C. 701 et seq. and 1396 et seq.);

(II) Centers in the State; and

(III) the State protection and advocacy system; and

(ii) representatives, at all times, of local and nongovernmental agencies, and private nonprofit groups concerned with services for individuals with developmental disabilities in the State in which such agencies and groups are located.

(B) **AUTHORITY AND LIMITATIONS**- The representatives described in subparagraph (A) shall--

(i) have sufficient authority to engage in policy planning and implementation on behalf of the department, agency, or program such representatives represent; and

(ii) recuse themselves from any discussion of grants or contracts for which such representatives' departments, agencies, or programs are grantees, contractors, or applicants and comply with the conflict of interest assurance requirement under section 124(c)(5)(D).

(5) **COMPOSITION OF MEMBERSHIP WITH DEVELOPMENTAL DISABILITIES**- Of the members of the Council described in paragraph (3)--

(A) 1/3 shall be individuals with developmental disabilities described in paragraph (3)(A)(i);

(B) 1/3 shall be parents or guardians of children with developmental disabilities described in paragraph (3)(A)(ii), or immediate relatives or guardians of adults with developmental disabilities described in paragraph (3)(A)(iii); and

(C) 1/3 shall be a combination of individuals described in paragraph (3)(A).

(6) **INSTITUTIONALIZED INDIVIDUALS**-

(A) **IN GENERAL**- Of the members of the Council described in paragraph (5), at least 1 shall be an immediate relative or guardian of an individual with a developmental disability who resides or previously resided in an institution or shall be an individual with a developmental disability who resides or previously resided in an institution.

(B) **LIMITATION**- Subparagraph (A) shall not apply with respect to a State if such an individual does not reside in that State.

(c) **COUNCIL RESPONSIBILITIES**-

(1) **IN GENERAL**- A Council, through Council members, staff, consultants, contractors, or subgrantees, shall have the responsibilities described in paragraphs (2) through (10).

(2) **ADVOCACY, CAPACITY BUILDING, AND SYSTEMIC CHANGE ACTIVITIES**- The Council shall serve as an advocate for individuals with developmental disabilities and conduct or support programs, projects, and activities that carry out the purpose of this subtitle.

(3) **EXAMINATION OF GOALS**- At the end of each grant year, each Council shall--

(A) determine the extent to which each goal of the Council was achieved for that year;

(B) determine to the extent that each goal was not achieved, the factors that impeded the achievement;

(C) determine needs that require amendment of the 5-year strategic State plan required under section 124;

(D) separately determine the information on the self-advocacy goal described in section 124(c)(4)(A)(ii); and

(E) determine customer satisfaction with Council supported or conducted activities.

(4) **STATE PLAN DEVELOPMENT**- The Council shall develop the State plan and submit the State plan to the Secretary after consultation with the designated State agency under the State plan. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring consistency of the plan with State law.

(5) **STATE PLAN IMPLEMENTATION**-

(A) **IN GENERAL**- The Council shall implement the State plan by conducting and supporting advocacy, capacity building, and systemic change activities such as those described in subparagraphs (B) through (L).

(B) **OUTREACH**- The Council may support and conduct outreach activities to identify individuals with developmental disabilities and their families who otherwise might not come to the attention of the Council and assist and enable the individuals and families to obtain services, individualized supports, and other forms of assistance, including access to special adaptation of generic community services or specialized services.

(C) **TRAINING**- The Council may support and conduct training for persons who are individuals with developmental disabilities, their families, and personnel (including professionals, paraprofessionals, students, volunteers, and other community members) to enable such persons to obtain access to, or to provide, community services, individualized supports, and other forms of assistance, including special adaptation of generic community services or specialized services for individuals with developmental disabilities and their families. To the extent that the Council supports or conducts training activities under this subparagraph, such activities shall contribute to the achievement of the purpose of this subtitle.

(D) **TECHNICAL ASSISTANCE**- The Council may support and conduct technical assistance activities to assist public and private entities to contribute to the achievement of the purpose of this subtitle.

(E) **SUPPORTING AND EDUCATING COMMUNITIES**- The Council may support and conduct activities to assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families--

(i) by encouraging local networks to provide informal and formal supports;

(ii) through education; and

(iii) by enabling neighborhoods and communities to offer such individuals and their families access to and use of services, resources, and opportunities.

(F) **INTERAGENCY COLLABORATION AND COORDINATION**- The Council may support and conduct activities to promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.

(G) **COORDINATION WITH RELATED COUNCILS, COMMITTEES, AND PROGRAMS**- The Council may support and conduct activities to enhance coordination of services with--

(i) other councils, entities, or committees, authorized by Federal or State law, concerning individuals with disabilities (such as the State interagency coordinating council established under subtitle C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.), the State Rehabilitation Council and the Statewide Independent Living Council established under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the State mental health planning council established under subtitle B of title XIX of the Public Health Service Act (42 U.S.C. 300x-1 et seq.), and the activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), and entities carrying out other similar councils, entities, or committees);

(ii) parent training and information centers under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.) and other entities carrying out federally funded projects that assist parents of children with disabilities; and

(iii) other groups interested in advocacy, capacity building, and systemic change activities to benefit individuals with disabilities.

(H) **BARRIER ELIMINATION, SYSTEMS DESIGN AND REDESIGN**- The Council may support and conduct activities to eliminate barriers to access and use of community services by individuals with developmental disabilities, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State plan.

(I) **COALITION DEVELOPMENT AND CITIZEN PARTICIPATION**- The Council may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.

(J) **INFORMING POLICYMAKERS**- The Council may support and conduct activities to provide information to policymakers by supporting and conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations. The Council may provide the information directly to Federal, State, and local policymakers, including Congress, the Federal executive branch, the Governors, State legislatures, and State agencies, in order to increase the ability of such policymakers to offer opportunities and to enhance or adapt generic services to meet the needs of, or provide specialized services to, individuals with developmental disabilities and their families.

(K) **DEMONSTRATION OF NEW APPROACHES TO SERVICES AND SUPPORTS**-

(i) **IN GENERAL**- The Council may support and conduct, on a time-limited basis, activities to demonstrate new approaches to serving individuals with developmental disabilities that are a part of an overall strategy for systemic change. The strategy may involve the education of policymakers and the public about how to deliver effectively, to individuals with developmental disabilities and their families, services, supports, and assistance that contribute to the achievement of the purpose of this subtitle.

(ii) **SOURCES OF FUNDING**- The Council may carry out this subparagraph by supporting and conducting demonstration activities through sources of funding other than funding provided under this subtitle, and by assisting entities conducting demonstration activities to develop strategies for securing funding from other sources.

(L) **OTHER ACTIVITIES**- The Council may support and conduct other advocacy, capacity building, and systemic change activities to promote the development of a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this subtitle.

(6) **REVIEW OF DESIGNATED STATE AGENCY**- The Council shall periodically review the designated State agency and activities carried out under this subtitle by the designated State agency and make any recommendations for change to the Governor.

(7) **REPORTS**- Beginning in fiscal year 2002, the Council shall annually prepare and transmit to the Secretary a report. Each report shall be in a form prescribed by the Secretary by regulation under section 104(b). Each report shall contain information about the progress made by the Council in achieving the goals of the Council (as specified in section 124(c)(4)), including--

(A) a description of the extent to which the goals were achieved;

(B) a description of the strategies that contributed to achieving the goals;

(C) to the extent to which the goals were not achieved, a description of factors that impeded the achievement;

(D) separate information on the self-advocacy goal described in section 124(c)(4)(A)(ii);

(E)(i) as appropriate, an update on the results of the comprehensive review and analysis described in section 124(c)(3); and

(ii) information on consumer satisfaction with Council supported or conducted activities;

(F)(i) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities in Intermediate Care Facilities (Mental Retardation) receive; and

(ii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)) receive;

(G) an accounting of the manner in which funds paid to the State under this subtitle for a fiscal year were expended;

(H) a description of--

(i) resources made available to carry out activities to assist individuals with developmental disabilities that are directly attributable to Council actions; and

(ii) resources made available for such activities that are undertaken by the Council in collaboration with other entities; and

(I) a description of the method by which the Council will widely disseminate the annual report to affected constituencies and the general public and will assure that the report is available in accessible formats.

(8) **BUDGET**- Each Council shall prepare, approve, and implement a budget using amounts paid to the State under this subtitle to fund and implement all programs, projects, and activities carried out under this subtitle, including--

(A)(i) conducting such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council; and

(ii) as determined in Council policy--

(I) reimbursing members of the Council for reasonable and necessary expenses (including expenses for child care and personal assistance services) for attending Council meetings and performing Council duties;

(II) paying a stipend to a member of the Council, if such member is not employed or must forfeit wages from other employment, to attend Council meetings and perform other Council duties;

(III) supporting Council member and staff travel to authorized training and technical assistance activities including in-service training and leadership development activities; and

(IV) carrying out appropriate subcontracting activities;

(B) hiring and maintaining such numbers and types of staff (qualified by training and experience) and obtaining the services of such professional, consulting, technical, and clerical staff (qualified by training and experience), consistent with State law, as the Council determines to be necessary to carry out the functions of the Council under this subtitle, except that such State shall not apply hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council, to the extent that such policies would impact the staff or functions funded with Federal funds, or would prevent the Council from carrying out the functions of the Council under this subtitle; and

(C) directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the State plan approved under section 124.

(9) **STAFF HIRING AND SUPERVISION**- The Council shall, consistent with State law, recruit and hire a Director of the Council, should the position of Director become vacant, and supervise and annually evaluate the Director. The Director shall hire, supervise, and annually evaluate the staff of the Council. Council recruitment, hiring, and dismissal of staff shall be conducted in a manner consistent with Federal and State nondiscrimination laws. Dismissal of personnel shall be conducted in a manner consistent with State law and personnel policies.

(10) **STAFF ASSIGNMENTS**- The staff of the Council, while working for the Council, shall be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and shall not be assigned duties by the designated State agency or any other agency or entity of the State.

(11) **CONSTRUCTION**- Nothing in this title shall be construed to authorize a Council to direct, control, or exercise any policymaking authority or administrative authority over any program assisted under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.) or the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.).

(d) **DESIGNATED STATE AGENCY**-

(1) **IN GENERAL**- Each State that receives assistance under this subtitle shall designate a State agency that shall, on behalf of the State, provide support to the Council. After the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994 (Public Law 103-230), any designation of a State agency under this paragraph shall be made in accordance with the requirements of this subsection.

(2) **DESIGNATION**-

(A) **TYPE OF AGENCY**- Except as provided in this subsection, the designated State agency shall be--

(i) the Council if such Council may be the designated State agency under the laws of the State;

(ii) a State agency that does not provide or pay for services for individuals with developmental disabilities; or

(iii) a State office, including the immediate office of the Governor of the State or a State planning office.

(B) **CONDITIONS FOR CONTINUATION OF STATE SERVICE AGENCY DESIGNATION**-

(i) **DESIGNATION BEFORE ENACTMENT**- If a State agency that provides or pays for services for individuals with developmental disabilities was a designated State agency for purposes of part B of the Developmental Disabilities Assistance and Bill of Rights Act on the date of enactment of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994, and the Governor of the State (or the legislature, where appropriate and in accordance with State law) determines prior to June 30, 1994, not to change the designation of such agency, such agency may continue to be a designated State agency for purposes of this subtitle.

(ii) **CRITERIA FOR CONTINUED DESIGNATION**- The determination, at the discretion of the Governor (or the legislature, as the case may be), shall be made after--

(I) the Governor has considered the comments and recommendations of the general public and a majority of the non-State agency members of the Council with respect to the designation of such State agency; and

(II) the Governor (or the legislature, as the case may be) has made an independent assessment that the designation of such agency will not interfere with the budget, personnel, priorities, or other action of the Council, and the ability of the Council to serve as an independent advocate for individuals with developmental disabilities.

(C) **REVIEW OF DESIGNATION**- The Council may request a review of and change in the designation of the designated State agency by the Governor (or the legislature, as the case may be). The Council shall provide documentation concerning the reason the Council desires a change to be made and make a recommendation to the Governor (or the legislature, as the case may be) regarding a preferred designated State agency.

(D) **APPEAL OF DESIGNATION**- After the review is completed under subparagraph (C), a majority of the non-State agency members of the Council may appeal to the Secretary for a review of and change in the designation of the designated State agency if the ability of the Council to serve as an independent advocate is not assured because of the actions or inactions of the designated State agency.

(3) **RESPONSIBILITIES**-

(A) **IN GENERAL**- The designated State agency shall, on behalf of the State, have the responsibilities described in subparagraphs (B) through (G).

(B) **SUPPORT SERVICES**- The designated State agency shall provide required assurances and support services as requested by and negotiated with the Council.

(C) **FISCAL RESPONSIBILITIES**- The designated State agency shall--

(i) receive, account for, and disburse funds under this subtitle based on the State plan required in section 124; and

(ii) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of, and accounting for, funds paid to the State under this subtitle.

(D) **RECORDS, ACCESS, AND FINANCIAL REPORTS**- The designated State agency shall keep and provide access to such records as the Secretary and the Council may determine to be necessary. The designated State agency, if other than the Council, shall provide timely financial reports at the request of the Council regarding the status of expenditures, obligations, and liquidation by the agency or the Council, and the use of the Federal and non-Federal shares described in section 126, by the agency or the Council.

(E) **NON-FEDERAL SHARE**- The designated State agency, if other than the Council, shall provide the required non-Federal share described in section 126(c).

(F) **ASSURANCES**- The designated State agency shall assist the Council in obtaining the appropriate State plan assurances and in ensuring that the plan is consistent with State law.

(G) **MEMORANDUM OF UNDERSTANDING**- On the request of the Council, the designated State agency shall enter into a memorandum of understanding with the Council delineating the roles and responsibilities of the designated State agency.

(4) **USE OF FUNDS FOR DESIGNATED STATE AGENCY RESPONSIBILITIES**-

(A) **CONDITION FOR FEDERAL FUNDING**-

(i) **IN GENERAL**- The Secretary shall provide amounts to a State under section 124(c)(5)(B)(vi) for a fiscal year only if the State expends an amount from State sources for carrying out the responsibilities of the designated State agency under paragraph (3) for the fiscal year that is not less than the total amount the State expended from such sources for carrying out similar responsibilities for the previous fiscal year.

(ii) **EXCEPTION**- Clause (i) shall not apply in a year in which the Council is the designated State agency.

(B) **SUPPORT SERVICES PROVIDED BY OTHER AGENCIES**- With the agreement of the designated State agency, the Council may use or contract with agencies other than the designated State agency to perform the functions of the designated State agency.

SEC. 126. FEDERAL AND NON-FEDERAL SHARE.

(a) **AGGREGATE COST**-

(1) **IN GENERAL**- Except as provided in paragraphs (2) and (3), the Federal share of the cost of all projects in a State supported by an allotment to the State under this subtitle may not be more than 75 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(2) **URBAN OR RURAL POVERTY AREAS**- In the case of projects whose activities or products target individuals with developmental disabilities who live in urban or rural poverty areas, as determined by the Secretary, the Federal share of the cost of all such projects may not be more than 90 percent of the aggregate necessary cost of such projects, as determined by the Secretary.

(3) **STATE PLAN ACTIVITIES**- In the case of projects undertaken by the Council or Council staff to implement State plan activities, the Federal share of the cost of all such projects may be not more than 100 percent of the aggregate necessary cost of such activities.

(b) **NONDUPLICATION**- In determining the amount of any State's Federal share of the cost of such projects incurred by such State under a State plan approved under section 124, the Secretary shall not consider--

(1) any portion of such cost that is financed by Federal funds provided under any provision of law other than section 122; and

(2) the amount of any non-Federal funds required to be expended as a condition of receipt of the Federal funds described in paragraph (1).

(c) **NON-FEDERAL SHARE**-

(1) **IN-KIND CONTRIBUTIONS**- The non-Federal share of the cost of any project supported by an allotment under this subtitle may be provided in cash or in kind, fairly evaluated, including plant, equipment, or services.

(2) **CONTRIBUTIONS OF POLITICAL SUBDIVISIONS AND PUBLIC OR PRIVATE ENTITIES**-

(A) **IN GENERAL**- Contributions to projects by a political subdivision of a State or by a public or private entity under an agreement with the State shall, subject to such limitations and conditions as the Secretary may by regulation prescribe under section 104(b), be considered to be contributions by such State, in the case of a project supported under this subtitle.

(B) **STATE CONTRIBUTIONS**- State contributions, including contributions by the designated State agency to provide support services to the Council pursuant to section 125(d)(4), may be counted as part of such State's non-Federal share of the cost of projects supported under this subtitle.

(3) **VARIATIONS OF THE NON-FEDERAL SHARE**- The non-Federal share required of each recipient of a grant from a Council under this subtitle may vary.

SEC. 127. WITHHOLDING OF PAYMENTS FOR PLANNING, ADMINISTRATION, AND SERVICES.

Whenever the Secretary, after providing reasonable notice and an opportunity for a hearing to the Council and the designated State agency, finds that--

(1) the Council or agency has failed to comply substantially with any of the provisions required by section 124 to be included in the State plan, particularly provisions required by paragraphs (4)(A) and (5)(B)(vii) of section 124(c), or with any of the provisions required by section 125(b)(3); or

(2) the Council or agency has failed to comply substantially with any regulations of the Secretary that are applicable to this subtitle,

the Secretary shall notify such Council and agency that the Secretary will not make further payments to the State under section 122 (or, in the discretion of the Secretary, that further payments to the State under section 122 for activities for which there is such failure), until the Secretary is satisfied that there will no longer be such failure. Until the Secretary is so satisfied, the Secretary shall make no further payments to the State under section 122, or shall limit further payments under section 122 to such State to activities for which there is no such failure.

SEC. 128. APPEALS BY STATES.

(a) **APPEAL**- If any State is dissatisfied with the Secretary's action under section 124(d)(3) or 127, such State may appeal to the United States court of appeals for the circuit in which such State is located, by filing a petition with such court not later than 60 days after such action.

(b) **FILING**- The clerk of the court shall transmit promptly a copy of the petition to the Secretary, or any officer designated by the Secretary for that purpose. The Secretary shall file promptly with the court the record of the proceedings on which the Secretary based the action, as provided in section 2112 of title 28, United States Code.

(c) **JURISDICTION**- Upon the filing of the petition, the court shall have jurisdiction to affirm the action of the Secretary or to set the action aside, in whole or in part, temporarily or permanently. Until the filing of the record, the Secretary may modify or set aside the order of the Secretary relating to the action.

(d) **FINDINGS AND REMAND**- The findings of the Secretary about the facts, if supported by substantial evidence, shall be conclusive, but the court, for good cause shown, may remand the case involved to the Secretary for further proceedings to take further evidence. On remand, the Secretary may make new or modified findings of fact and may modify the previous action of the Secretary, and shall file with the court the record of the further proceedings. Such new or modified findings of fact shall likewise be conclusive if supported by substantial evidence.

(e) **FINALITY**- The judgment of the court affirming or setting aside, in whole or in part, any action of the Secretary shall be final, subject to review by the Supreme Court of the United States upon certiorari or certification as provided in section 1254 of title 28, United States Code.

(f) **EFFECT**- The commencement of proceedings under this section shall not, unless so specifically ordered by a court, operate as a stay of the Secretary's action.

SEC. 129. AUTHORIZATION OF APPROPRIATIONS.

(a) **FUNDING FOR STATE ALLOTMENTS**- Except as described in subsection (b), there are authorized to be appropriated for allotments under section 122 $76,000,000 for fiscal year 2001 and such sums as may be necessary for each of fiscal years 2002 through 2007.

(b) **RESERVATION FOR TECHNICAL ASSISTANCE**-

(1) **LOWER APPROPRIATION YEARS**- For any fiscal year for which the amount appropriated under subsection (a) is less than $76,000,000, the Secretary shall reserve funds in accordance with section 163(c) to provide technical assistance to entities funded under this subtitle.

(2) **HIGHER APPROPRIATION YEARS**- For any fiscal year for which the amount appropriated under subsection (a) is not less than $76,000,000, the Secretary shall reserve not less than $300,000 and not more than 1 percent of the amount appropriated under subsection (a) to provide technical assistance to entities funded under this subtitle.

Subtitle C--Protection and Advocacy of Individual Rights

SEC. 141. PURPOSE.

SEC. 142. ALLOTMENTS AND PAYMENTS.

SEC. 143. SYSTEM REQUIRED.

SEC. 144. ADMINISTRATION.

SEC. 145. AUTHORIZATION OF APPROPRIATIONS.

Subtitle D--National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service

SEC. 151. GRANT AUTHORITY.

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SEC. 161. PURPOSE.

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TITLE II--FAMILY SUPPORT

SEC. 201. SHORT TITLE.

This title may be cited as the `Families of Children With Disabilities Support Act of 2000'.

SEC. 202. FINDINGS, PURPOSES, AND POLICY.

SEC. 203. DEFINITIONS AND SPECIAL RULE.

SEC. 204. GRANTS TO STATES.

SEC. 205. APPLICATION.

SEC. 206. DESIGNATION OF THE LEAD ENTITY.

SEC. 207. AUTHORIZED ACTIVITIES.

SEC. 208. REPORTING.

SEC. 209. TECHNICAL ASSISTANCE.

SEC. 210. EVALUATION.

SEC. 211. PROJECTS OF NATIONAL SIGNIFICANCE.

SEC. 212. AUTHORIZATION OF APPROPRIATIONS.

TITLE III--PROGRAM FOR DIRECT SUPPORT WORKERS WHO ASSIST INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

SEC. 301. FINDINGS.

SEC. 302. DEFINITIONS.

SEC. 303. REACHING UP SCHOLARSHIP PROGRAM.

SEC. 304. STAFF DEVELOPMENT CURRICULUM AUTHORIZATION.

SEC. 305. AUTHORIZATION OF APPROPRIATIONS.

TITLE IV--REPEAL

SEC. 401. REPEAL.

Maine Revised Statutes

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES HEADING: PL 1995, C. 560, PT. K, §7 (RPR); 2001, C. 354, §3 (AMD)

Chapter 17: DEVELOPMENTAL DISABILITIES HEADING: PL 2003, C. 417, §3 (NEW); §4 (AFF)

§17001. Maine Developmental Disabilities Council

1. Establishment. The Maine Developmental Disabilities Council, referred to in this section as "the council," is established as authorized by Title 5, section 12004-I, subsection 66 and in accordance with the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402.
[2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF) .]

2. Status. The council is a public instrumentality of the State, and the exercise of the power conferred by this section is the performance of essential governmental functions. The council may not be considered a state agency for any purposes, including, but not limited to, budgeting, accounts and control, auditing and purchasing.
[2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF) .]

3. Appointments. The Governor shall appoint appropriate representatives to the council, as required under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, upon consideration of recommendations made by current members of the council.
[2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF) .]

4. Duties. The council shall perform its duties in compliance with the requirements of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.
[2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF) .]

5. Designated state agency. Notwithstanding subsection 2, the Department of Administrative and Financial Services is the designated state agency for the purposes of the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402. As the designated state agency, the department shall meet all requirements specified in 42 United States Code, Section 15025 but may assume no liabilities other than those set forth in 42 United States Code, Section 15025 in connection with the receipt of federal funds for the purpose of disbursement to the council.
[2005, c. 519, Pt. BB, §1 (AMD) .]

6. Council personnel and members. As of the effective date of this section:

A. All employees assigned to the council who state that they wish to continue as employees of the council must be transferred from state employment to employment of the council in its capacity as an independent advisory agency; [2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF).]

B. Accrued fringe benefits from state employment of transferred personnel, including, but not limited to, vacation and sick leave, health and life insurance and retirement credits, remain available to the transferred personnel; [2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF).]

C. Members and employees of the council are not considered state employees for the purpose of the state civil service provisions of Title 5, Part 2 and chapter 372 or for any other purpose except as follows.

(1) Employees of the council, including employees hired after the effective date of this section, are deemed state employees for the purposes of the state retirement provisions of Title 5, Part 20 and the state employee health insurance program under Title 5, chapter 13, subchapter 2.

(2) For purposes of the Maine Tort Claims Act, the council is deemed a governmental entity and its employees and members are deemed employees as those terms are defined in Title 14, section 8102; and [2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF).]

D. An employee of the council may return to state employment at any time up to 2 years from the effective date of this section. Employees expressing such a preference must be placed on the appropriate registers maintained by the Department of Administrative and Financial Services, Bureau of Human Resources and must be treated as though on recall in accordance with current collective bargaining provisions. [2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF).]

[2003, c. 417, §3 (NEW); 2003, c. 417, §4 (AFF) .]

7. Council report. The council, pursuant to its duties under subsection 4, shall provide information from the comprehensive review and analysis of services, supports and other assistance for persons with disabilities required by 42 United States Code, Chapter 144, Section 15024 (c) (3) to the Legislature by January 31st of each year.

[2007, c. 152, §2 (NEW) .]

SECTION HISTORY

2003, c. 417, §3 (NEW). 2003, c. 417, §4 (AFF). 2005, c. 137, §1 (AMD). 2005, c. 519, §BB1 (AMD). 2007, c. 152, §2 (AMD).

Memorandum of Understanding Between the Maine Developmental Disabilities Council and the Department of Administrative and Financial Services

The Maine Developmental Disabilities Council (MDDC) and the Department of Administrative and Financial Services (DAFS) agree as follows:

1. Each party shall meet its obligations set out in 42 U.S.C. §§15021-15029.

2. The parties agree that MDDC is a public instrumentality as set out in its enabling legislation at 34-B M.R.S.A. §17001.

3. DAFS shall not interfere with any activity of MDDC. However, DAFS may request and MDDC shall provide information in order for DAFS to carry out the responsibilities assigned to it as the "designated state agency" in accordance with 42 U.S.C. §§15025 and 15026. MDDC hereby agrees to provide such information in a timely fashion to enable DAFS to meet its responsibilities to the federal Department of Health and Human Services.

4. With regard to "assurances and support services as requested by and negotiated with the Council" that 42 U.S.C. §15025(d)(3)(B) requires DAFS to provide, the parties hereby agree that these shall be limited to the following:

a. DAFS shall pay federal funds to MDDC as requested by the submission of quarterly invoices to DAFS by MDDC in accordance with their contractual terms;

b. MDDC shall prepare, validate, and submit two reports required annually (ADD-02B and ADD-02) to be submitted to the federal authorities describing the use of federal funds. DAFS will certify these reports based on payment records and a review of MDDC's audited financial statements and/or other financial records.

c. To the extent that any dollar value must be assigned to the work that DAFS performs as the designated state agency, DAFS will calculate that value for inclusion in any report to the federal authorities.

d. With regard to the "non-Federal share" that 42 U.S.C. §15025(d)(3)(E) requires the State to provide, the State will provide that share through in-kind support for projects whose activities or products are related to MDDC activities, as well as the value of the work required of DAFS to perform as the designated state agency. The non-federal share shall be jointly identified and quantified by the parties.

e. With regard to "timely financial reports at the request of the Council regarding the status of expenditures," DAFS will provide to MDDC sufficient information throughout the year to permit MDDC to meet its reporting requirements concerning any federal funds received for use by MDDC, any federal funds advanced to MDDC and any balance of federal funds available to MDDC for the period of the report.

f. With regard to the requirement that DAFS "assist the Council in obtaining the appropriate State plan assurances and in ensuring that the plan is consistent with State law," a

letter signed by the Commissioner will be submitted periodically to the federal Secretary to provide these assurances upon the request of MDDC.

8. To fulfill its responsibilities as the Designated State Agency to review and certify the annual ADD-02 and ADD-02B reports and to request cash in compliance with federal requirements, DAFS will require interim financial statements from MDDC semi-annually and MDDC's audited financial statements for each year as soon as they become available. However, since review of these documents can be only a general review for reasonableness, all representations regarding expenditures shown on the ADD-02B and ADD-02 reports are the responsibility of MDDC; likewise, it is the responsibility of MDDC to submit invoices in compliance with the terms of the contract and federal cash management requirements.

9. In connection to any periodic or other review by MDDC of the designated state agency and its activities in connection to its receipt of federal funds intended for MDDC use, MDDC agrees to provide a draft copy of any report generated to the Commissioner of DAFS for comment and input before the report's submission to any other entity.

10. DAFS does not assume any liability or agree to indemnify or otherwise defend MDDC for any liability that may result in connection with MDDC's use of federal funds received by DAFS for MDDC's use and disbursed to MDDC except as provided in 42 U.S.C. §§15021-15029. By signing this memorandum of understanding, DAFS does not waive any defenses, processes or immunities to which it may be entitled in the event of any disallowance action taken by the federal Department of Health and Human Services against MDDC.

11. This memorandum of understanding will be effective as of the signature dates of the two parties. This agreement will remain in effect until either party notifies the other in advance that they will be terminating it.

DATED: 7/21/11

Julia J. Bell

Julia J. Bell, Executive Director
Maine Developmental Disabilities Council
225 Western Avenue
Augusta, Maine 04330

DATED: 7/26/11

Raymond Girouard
Director, DAFS-DHHS Service Center
Department of Administrative and Financial Services
11 State House Station
Augusta, Maine 04333-0078

Maine Developmental Disabilities Council

COUNCIL MEMBERSHIP
As of March 12, 2012

Patrick Adams
Family Member - Newburgh

Laura Antranigian
Self-Advocate - Portland

Peter Auger
Dept. of Health & Human Services
(Title XIX Adult Svs. rep)

Jodi Benvie
Disability Rights Center of Maine

Maggie Carr
Non-Governmental Organization

Alan Cobo-Lewis
Family Member - Orono

Deborah Drinkwater
Dept. of Health & Human Services
(Older Americans Act rep.)

Kim Esposito
Self-Advocate - Yarmouth

Eric McVay
Self-Advocate - Hampden

Avery Olmstead
Self-Advocate - Old Town

Christian Powers
Self-Advocate - Eagle Lake

Marc Roix
Self-Advocate - Sidney

Susan Russell
Center for Community Inclusion &
Disability Studies

Joan Smyrski
Dept. of Health & Human Services
(Title XIX Children's Svs. rep)

Hillary Steinau
Family Member - Camden

Dennis Strout
Non-Governmental Organization

Teresa Valente
Family Member - Portland

Toni G. Wall
Dept. of Health & Human Services
(Title V representative)

Elinor Weissman
Department of Labor
(Rehabilitation Svs rep)

Sheree Wess
Family Member - East Winthrop

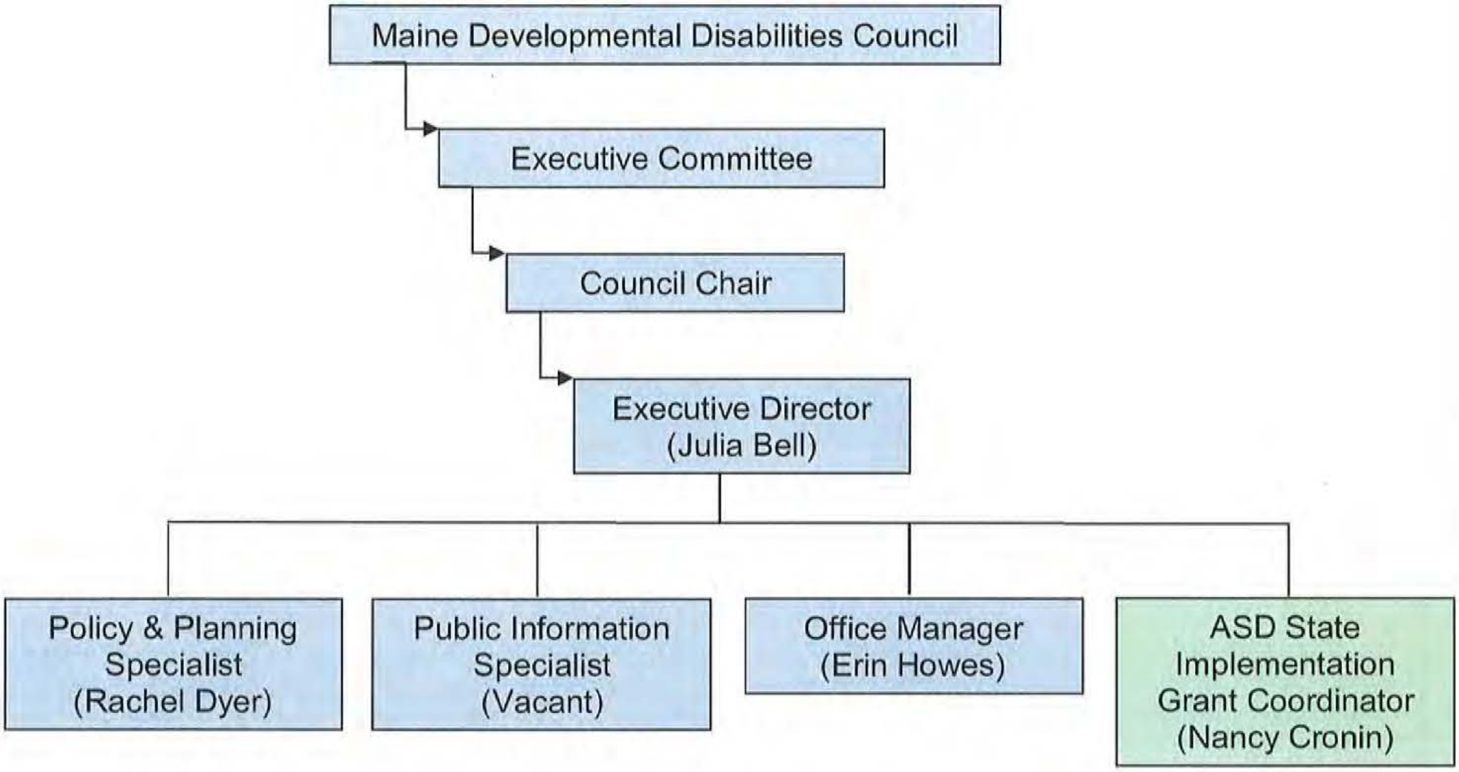
Jean Youde
Family Member - Hallowell

Vacant
Department of Education

Five Self Advocate/Family Member Seats Vacant as of 3/12/12.

MAINE DEVELOPMENTAL DISABILITIES COUNCIL

ORGANIZATIONAL CHART



🟦 Annual Allotment pursuant to the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000

🟩 Contract with Maine Department of Health and Human Services to manage three-year grant from the federal Health Resources and Services Administration (HRSA) September 1, 2010 – August 31, 2013

March 12, 2012

Maine Developmental
Disabilities Council

Five-Year State Plan

October 1, 2011 – September 30, 2016

Julia J. Bell, Executive Director
Maine Developmental Disabilities Council
139 State House Station
Augusta, ME, 04333
207-287-4213
www.MaineDDC.org

Table of Contents

Section I: Council Identification

PART A: State Plan Period: October 1, 2011 through September 30, 2016

PART B: Contact:

Person: Julia J. Bell, Executive Director

Telephone: (207) 287-4215

E-Mail: julia.j.bell@maine.gov

PART C: Council Establishment:

Date of Establishment: 1971-Jun-10

Authorization: State Statute

Authorization Citation: Title 34-B Maine Revised Statutes Annotated Chapter 17

PART D: Council Membership [Section 125(b)(1)-(6)]

Council Membership Rotation Plan:

Per Council By-Laws, Article 9: Appointments:

Section 2: With the exception of legally required members, the term of appointment shall be two years. Members may be reappointed for up to three additional consecutive terms. Individuals who have completed the maximum number of terms may reapply for membership after one term of non-membership. In the event that a timely appointment has not been made, the incumbent member may continue to serve in the interim.

Section 3. Replacement appointments for unexpired terms shall be made as necessary to fill vacancies. Replacement members shall serve the remaining period of the unexpired term and may be reappointed for up to four full additional consecutive terms. Individuals who have completed the maximum number of terms may reapply for membership after one term of non-membership.

Section 4. State agency, UCEDD, and P&A representatives shall serve without term expirations.

Council Members

Name	Code	Organization	Appointed	Term Date	Alt/Proxy State Rep Name
Adams, Patrick	B2		2010-Aug-05	2012-Aug-05	
Antranigian, Laura	B1		2004-Aug-05	2012-Aug-05	
Bowen, Steven	A2	Maine Department of Education			Stockford, David
Carr, Margaret	A7	Maine Parent Federation	2010-Aug-05	2012-Aug-05	
Cobo-Lewis, Alan	B2		2007-Aug-05	2013-Aug-05	
Esposito, Kim	C1		2008-Aug-05	2012-Aug-05	
Mayhew, Mary	A8	Children with Spec. He Care Needs, Maine Dept of Health & Human Svs.			Wall, Toni
Mayhew, Mary	A4	Developmental Services, Maine Dept of Health & Human Services			Auger, Peter
yhew, Mary	A3	Elder Services, Maine Dept of Health & Human Services			Drinkwater, Deborah
Mayhew, Mary	A4	Children's Beh. Health Svs., Maine Dept of Health & Human Svs.			Smyrski, Joan
McVay, Eric	B1		2006-Aug-05	2012-Aug-05	
Moody, Kim	A5	Disability Rights Center of Maine	1969-Dec-31	1969-Dec-31	Benvie, Jodi
Pelletier, Kile	B1		2006-Aug-05	2012-Aug-05	
Potter, Melissa	B2		2010-Aug-05	2012-Aug-05	
Powers, Christian	B1		2011-Aug-05	2013-Aug-05	
Roix, Marc	B1		2008-Aug-05	2012-Aug-05	
Russell, Susan	A6	Center for Community Inclusion & Disabilities Studies			
Steinau, Hillary	B2		2008-Aug-05	2012-Aug-05	
Strout, Dennis	A7	Momentum, Inc.	2010-Aug-05	2012-Aug-05	
Vacant	B2				

Vacant	B1				
Vacant	B1				
Valente, Theresa	B3		2010-Aug-05	2012-Aug-05	
Wagner-Peck, Kari	B2		2011-Aug-05	2013-Aug-05	
Wess, Sheree	B3		2004-Aug-05	2012-Aug-05	
Winglass, Robert	A1	Maine Department of Labor			Elinor Weissman
Youde, Jean	B2		2005-Aug-05	2013-Aug-05	

Council Membership Codes

<u>Agency/Organization Representatives</u>

A1: Rehab Act	A2: IDEA	A3: Older American Act	A4: SSA/Title X1X
A5: UCEDD	A6: P&A	A7: NGO/Local	A8: SSA/TitleV

<u>Citizen Member Representatives</u>

B1: Individual w/DD	B2: Parent/Guardian of Child w/DD	B3: Immediate Relative/Guardian of adult w/mental impairment
C1: Individual now/ever in institution	C2: Immediate Relative/Guardian of Individual in institution

Council Staff

Name	**Position or Working Title**	**FT/PT %**
Bell, Julia J.	Executive Director	100.00%
Cronin, Nancy E.	PDD Systems Change Coordinator	100.00%
Dyer, Rachel M.	Policy & Research Specialist	100.00%
Howes, Erin L.	Office Manager	100.00%
Young, Kathleen E.	Public Information Specialist	100.00%

Section II: Designated State Agency

PART A: The designated state agency is:

Agency Name: Maine Department of Administrative & Financial Services

Agency Address: 78 State House Station, Augusta, ME, 04333

Telephone: (207) 624-7800

Fax: (207) 624-7804

PART B: Direct Services: [Section 125(d)(2)(A)-(B)]

The DSA does not provide direct services to persons with developmental disabilities.

PART C: Memorandum of Understanding/Agreement: [Section 125(d)(3)(G)]

The DSA has a Memorandum/Agreement with the Council.

PART D: DSA Roles and Responsibilities related to Council: [Section 125(d)(3)(A)-(G)]

DSA is responsible for drawing down federal allotment, preparation of federal cash receipt/disbursements form, and processing of invoices received from DD Council.

PART E: Calendar Year DSA was Designated: [Section 125(d)(2)(B)]: 2005

Section III: Comprehensive Review and Analysis [Section 124(c)(3)]

INTRODUCTION: A broad overview of the Comprehensive Review and Analysis conducted by the Council.

The Council utilized a multi-faceted process for collecting input and evaluating the issues that should be addressed in the next five-year State Plan. Ten public meetings were held in communities across the state, and the Council also met with other groups and provided an on-line survey on its website. Council members wanted to hear from as many interested parties as possible from all parts of this large state. These outreach efforts were advertised through public media, email networks, and through other public and private groups (the statewide self-advocates' organization, family and service providers' organizations, and state agencies, etc.).

The Council formed three workgroups which met regularly over a 6-month period to review state and national reports and data, and to hear from a wide array of stakeholders regarding current issues and concerns. The committees distilled all of the information gathered and presented their reports to the full Council at a two-day retreat in February, 2011; these served as the basis for the drafting of proposed goals and objectives for the next State Plan.

The proposed Goals and Objectives were published on the Council's website with an on-line survey to collect public comment. The Council again sought input through public and private organizations and their networks, through its connection with the statewide self-advocates' organization and family organizations, and the Council's email list of disability organizations and other interested parties. Input provided during the next six weeks was then reviewed by the Council in June, 2011, and resulted in some final adjustments to the State Plan prior to the Council's final approval at that meeting.

In the development of the State Plan, several general characteristics of the state were acknowledged which affect all Maine residents. Our state ranks in the bottom fifth in population, but has the highest percentage of residents over the age of 65, according to the latest U.S. Census. Maine is also a very rural state, with only three metro areas, which contain nearly 60% of the state's population. Maine has a statewide poverty rate (percentage of the population living at or below the federal poverty level) of 12.6%, with a higher rate in the large, rural northern counties of 14-18%.

Those counties also have fewer health care providers available, and residents must travel long distances to get specialty care, in particular. As a positive note, Maine has one of the highest rates of health insurance coverage in the country, but this also reflects one of the highest percentages of individuals covered by Medicaid in comparison to other states.

Several issues identified have a disproportionate effect on persons with developmental disabilities and their families. These include higher rates of poverty, as well as un- and underemployment, chronic difficulty accessing qualified health care providers, challenges in accessing early intervention and public education services, and limited availability and accessibility of public transportation and affordable housing. Individuals and families also commented on restrictive eligibility criteria for services and inadequate funding levels that result in waiting lists, and services and supports being unavailable in some cases, even when the person is found eligible and funding is allocated. Other issues identified include: lack of accessibility (including violations of the ADA), attitudinal barriers (from low expectations to bullying), lack of and/or inaccurate information, and lack of or poorly-coordinated supports.

This state plan has been developed in the context of a prolonged and severe economic downturn and a significantly altered political environment. While these factors have not resulted in large scale cuts to services so far, the Council is very concerned about the state's capacity to meet the needs of its residents with developmental disabilities, particularly those of young children and those on the growing waitlists (largely young adults).

PART A: State Information:

Racial and Ethnic Diversity of the State Population:

Race/Ethnicity	**Percentage of Population**
White alone	96.1%
Black or African American alone	1.2%
American Indian and Alaska Native alone	0.6%
Asian alone	1%
Native Hawaiian and Other Pacific Islander alone	0%
Hispanic or Latino of any race	1.3%
Some other race alone	0.4%
Two or more races:	1.1%

Poverty Rate: 12.6%

State Disability Characteristics:

a) Prevalence of Developmental Disabilities in the State: 23,910, using Gollway estimate 1.8%

b) Residential Settings:

Year	Total Served	A. Number Served in Setting of 6 or less (per 100,000)	B. Number Served in Setting of 7 or more (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
2009	270	242	28	41	60
2008	274	246	28	41	59
2007	192	163	29	41	57
2006	199	162	37	41	54
2005	200	162	38	42	50

c) Demographic Information about People with Disabilities:

People in the State with a Disability	Percentage
Population 5 to 17 years	7.8%
Population 18 to 64 years	13.9%
Population 65 years and over	30.4%

Race and Hispanic or Latino Origin of People with a Disability	Percentage
White alone	16.2%
Black or African American alone	10.5%
American Indian and Alaska Native alone	31%
Asian alone	5.9%
Native Hawaiian and Other Pacific Islander alone	0%
Some other race alone	7.5%
Two or more races	20.1%
While alone, not Hispanic or Latino	16.2%
Hispanic or Latino (of any race)	14.3%

Employment Status Population Age 16 and Over	Percentage with a Disability	Percentage without a Disability
Employed	24.8%	75.2%
Not in Labor Force	61.1%	38.9%

Education Attainment Population Age 25 and Over	Percentage with a Disability	Percentage without a Disability
Less than High School graduate	18.2%	5.3%
High School graduate, GED, or alternative	40.7%	33.7%
Some college or associate's degree	30.6%	34.3%
Bachelor's degree or higher	10.5%	26.7%

Earnings in the past 12 months Population Age 16 and Over with Earnings	**Percentage with a Disability**	**Percentage without a Disability**
$ 1 to $4,999 or loss	34.7%	23.3%
$ 5,000 to $ 14,999	11.8%	8.6%
$ 15,000 to $ 24,999	16.5%	16.8%
$ 25,000 to $ 34,999	13.2%	15.6%

Poverty Status Population Age 16 and Over	**Percentage with a Disability**	**Percentage without a Disability**
Below 100 percent of the poverty level	21.4%	11.3%
100 to 149 percent of the poverty level	17%	9.5%
At or above 150 percent of the poverty level	61.7%	79.3%

PART B: Portrait of the State Services [Section 124(c)(3)(A and B)]:

(i) Health/Healthcare:

Maine has one of the lowest uninsured rates for children in the U.S. - 95% have health insurance coverage, with more than half covered by MaineCare. Families with incomes up to 200% FPL qualify for MaineCare, and children with disabilities may qualify under the Katie Beckett option, if family income is above 200% FPL, if their needs meet institutional level of care requirements).

Most adults with developmental disabilities are also eligible for MaineCare, which is recognized as among the most comprehensive state health plans. However, problems with MaineCare's claims processing system 2 years ago resulted in many providers quitting the program. Also, families and service providers report that recent changes in the structure and eligibility criteria for MaineCare services for children have resulted in lack of coverage for needed services, including various therapies and home- and community-based supports. Some individuals with developmental disabilities who are "dually eligible" also report significant difficulty accessing services, especially mental health services, due to payment issues.

As of January, 2011, private health insurers must cover costs for early intervention services for any young child with developmental disabilities: 1) up to $3,200/year for any early intervention services, and 2) any needed services for any child up to age 6 with an autism spectrum disorder (only limit allowed is $36,000/year for ABA services). Yet, major barriers still exist that complicate families accessing early intervention services for their children with disabilities/delays, with pediatric medical care, early intervention services thru Child Development Services (Part C, IDEA-funded) and EPSDT requirements for MaineCare-eligible children not working in tandem to assure children receive services as early as possible. A Developmental Disabilities Council project in 2008-2010 regarding early identification and early intervention services for young children with autism spectrum disorders documented complex procedures for eligibility determination, requirements for multiple service plans, and delays in obtaining critical diagnostic evaluations.

Limited data studies by the Maine CDC indicate that persons with developmental disabilities are less likely than people without disabilities to receive routine cancer screenings, more likely to be overweight or have other cardiac risk factors and are as much as 7x more likely to report having inadequate social support (a risk factor for health problems). In 2010 Maine's State Health Plan identified a disproportionate number of Mainers have disabilities (23.8% vs. national 15.1%) but did not address specific healthcare needs in depth. People with developmental disabilities have limited participation in public health education and intervention, despite having disparities related to lifestyle and access typically addressed by public health.

The Council heard from persons with developmental disabilities and their families, especially those with limited communication and/or challenging behavior, who reported difficulty accessing quality hospital, as well as community, care. Stakeholders reported difficulty accessing care during "transitions", such as from developmental to general pediatrics, pediatric to adult medical practices and general adult care to gerontology. Problems were also noted with accessing specialty care, especially psychiatry. This was corroborated by a 2007 legislative report confirming mental health services for adults with developmental disabilities as an area of need, with no specialized services for this group available.

Lack of access to dental care is a critical problem across Maine, especially due to an overall shortage of rural dentists and the fact that few community dentists will treat MaineCare patients (and even fewer will treat patients who take extra time or special skills). This limits dental services for children, especially those with disabilities. Adults who are covered by the comprehensive HCBS waiver are able to access dental care (through Department contracting or other arrangements), in segregated clinics that may be long distances from home with long waits for appointments. Dental care is not a covered Medicaid service for adults, so people with developmental disabilities not on one of the waivers may receive dental care in hospital emergency rooms or not at all.

(ii) Employment:

Maine's unemployment rate is hovering at levels not seen in 30 years. Under-employment is also a major problem. Maine ranked 37th in the nation for average household income in 2008 (the most recent available data year). The employment rate for persons with disabilities is lower than for the general population. In 2008 it was only 39.5%, with the rate for full year/full time employment at only 24.1%. Data pertaining (but not specific) to developmental disabilities were more grim: only 23.3% of persons with cognitive disabilities were employed. The rate for those with independent living disabilities was 20%, and for those with self-care disabilities, 19%.

Families report low expectations in schools and among other professionals for children with developmental disabilities to be employed when they reach adulthood. Few teenagers with developmental disabilities have paid jobs (a strong predictor for adult employment). Another limiting factor is the lack of reliable, affordable transportation in most areas of the state, especially for non-drivers, which severely limits work options.

Vocational Rehabilitation (VR) services are a critical part of the employment picture for Mainers with developmental disabilities. Eligibility for VR services is based upon a person's functional limitations. VR services may, however, also be dependent upon a person's eligibility for one of the two waiver programs for persons with Intellectual Disabilities or Autism. Those who receive services through one of the two waiver programs have access to long-term employment supports. Currently, about 21% are being provided these supports, which may be used to address pre-employment issues as well as ongoing job support. (Budget cuts in recent years have reduced the number of hours of support and the flexibility of how they may be used.) Persons ineligible for waiver services or on a waitlist for one of the waivers may have their VR services discontinued, if the person will need long-term job supports.

The VR program has several initiatives underway to improve services for persons with disabilities, including elimination of the waitlist that delayed services for many people for a year or more. VR has also improved career center services for persons with disabilities; expanded benefits counseling services; and developed new job seeker education programs, specifically targeted to youth and people with intellectual disabilities, and a new training module to improve services for persons with autism spectrum disorders.

Many concerns are raised about VR's limitations in meeting the needs of persons with developmental disabilities, especially lack of involvement with youth during the transition period while they are still in school; inconsistent levels of skill among VR staff in working with people with various types of disabilities; lack of access to long term job supports through VR; and overall low rates of employment achievement. The low rates of closure of VR services associated with successful placement in employment are noted specifically. In federal FY10, only 47% of VR cases serving clients with cognitive disabilities were closed with the person having obtained employment, and the success rate for case closures for persons with physical disabilities was 38% and for persons with mental health disabilities, 32%.

It is noteworthy that Maine eliminated funding for sheltered workshops in 2008. However, there are still a few businesses in the state that have federal subminimum wage certificates, which allow them to employ people for much less than minimum wage. These workers are overwhelmingly people with developmental disabilities, as other types of employment supports (primarily funded by the Office of Mental Health Services) cannot be used to support sub-minimum wage work.

A Maine chapter of the national APSE organization has also been formed in the past two years to increase advocacy efforts for the expansion of employment opportunities for persons with developmental disabilities. Maine APSE is partnering with Maine's P&A, the Council and other advocacy groups to promote an Employment First agenda and increase work opportunities for persons with developmental disabilities.

(iii) Formal and informal services and supports:

Maine is one of a minority of states that has no state-run developmental disability institutions. Persons with developmental disabilities who qualify for one of two HCBS waivers for persons with intellectual disabilities or autism spectrum disorders are eligible for a range of services, but eligibility criteria for these waivers are among the nation's most restrictive. About two-thirds of those served (approx. 2,875 persons) are covered under the comprehensive HCBS waiver, first created in 1987, with provider-owned group homes as the primary residential setting. Shared Living (called "adult foster care" by some) has been offered as another option on a limited basis. The community supports waiver, approved in 2007, provides funding for a more limited range of supports up to a capped dollar amount for approximately 1,400 persons; this waiver is intended to support persons remaining at home with their families. The state agency indicates that its focus will be on added flexibility and more resources to this waiver (when available) in order to serve more people, while reserving the comprehensive waiver only for those individuals who need residential services.

Ideally, this should promote community involvement and informal supports being available to the individual and family as well. However, families report that their children are not fully included in activities outside of school, such as camp, athletics, clubs and social events, and that children developmental disabilities are often increasingly socially isolated as they age. Even families who live in supportive communities and have cultivated strong social networks describe a dramatic lessening of non-familial (unpaid) support when a child leaves school.

Children with significant functional limitations, especially behavior-related, have historically been served in private non-medical institutions (pnmi) or in out-of-state institutions. A new waiver as of July, 2011 will provide specialized supports for 40 children/youth, and add 20 additional "slots" in 2012, and another 20 in 2013. There is strong concern that, while this will allow some children to move home from out-of-state or pnmi placements, it will not meet the needs of many other families in need of a higher level of in-home support services than is available otherwise. Families also express strong concern about the high turnover rate in direct support staff, and inadequate availability of staff to provide approved hours of service.

Adults with developmental disabilities who have physical disabilities may qualify for the self-directed personal supports waiver; however, this is a very small waiver program, and offers a capped number of hours per week, which does not meet the needs of individuals who need access to support on a 24-hour/day basis. This has resulted in many persons ending up in nursing homes, with no access to transportation or other supports that allow community participation.

The statewide self-advocates' organization, Speaking Up for Us (SUFU), promotes community integration, provides training on a variety of topics, and supports individuals with developmental disabilities being engaged in policymaking and other community activities. SUFU and the Council have noted that participation depends on SUFU staff providing support to individuals with developmental disabilities, rather than informal supports developing that provide ongoing assistance and allow SUFU resources to be diverted elsewhere.

Specialized activities, such as ones just for children with disabilities, e.g. a separate morning for children with autism to visit a museum or a ballet program for girls with Down syndrome, tend to get publicity. Adults with developmental disabilities often lack "valued roles" (such as that of "worker") and may lack social/communication skills to build or maintain informal support networks. Older adults with developmental disabilities, especially, may lack family connections on which to build. A specific issue brought to the attention of the Council recently is the lack of appropriate supports for individuals with Down Syndrome or other developmental disabilities who develop dementia-related disorders.

(iv) Interagency Initiatives:

Although efforts to increase integration have taken place and are underway, services and support for people with developmental disabilities continue to exist in silos. Interagency initiatives have varying degrees of meaningful engagement by persons with developmental disabilities, families, and advocates.

The Departments of Education (DOE) and Health & Human Services (DHHS) have recently rewritten their MOUs, but concerns continue to be raised by families and advocates regarding the lack of coordination that negatively impacts services. Both DOE and DHHS also participate in a variety of other interagency collaborations and entities addressing children's issues, including several interagency councils: the Children's Cabinet, the Children's Growth Council (the State Early Learning Council), the MaineCare Advisory Council and the Maine Advisory Council for the Education of Children with Disabilities, which serves as the sole advisory body for IDEA parts B and C. (Although MACECD has a large number of parents and advocate members – via the DDC and P&A – questions are raised as to whether there is adequate focus on early childhood issues.)

The Maine Transition Council, an interagency collaboration intended to improve transition services for youth eaving school and special education services for post-secondary endeavors and services, was defunded 2 years ago. While regional DHHS offices and local school districts work together in some areas of the state (often through the efforts of parent advocacy groups), there is no focus on systemic collaboration and planning between education and adult services. While families describe the "cliff" they and their young adult children face as they leave public education and DHHS-administered children's services, there is little coordination or sharing of data that would allow realistic planning to address the needs of young adults with developmental disabilities. Statutory directives for sharing of data regarding the numbers of students who will exit school in the near future and types of services they will need are ignored, and pending legislation would eliminate the requirements. This is alarming to families and advocates who are aware of the dramatic increase in numbers of youth with autism spectrum disorders who will be exiting school in the next few years (as already evidenced by the growth in waiting lists for adult DD services).

The Departments of Labor and Health & Human Services have collaborated in several areas regarding employment of persons with disabilities: by rewriting MOUs aimed at better coordination of services and supports, and through collaborative staff training and benefits counseling initiatives.

DOL also has a somewhat unusual initiative with the Department of Education to administer its RSA Assistive Technology funding through an independent organization, Maine CITE. Its position outside of DOL has broadened the awareness of the program and those accessing its services. Maine CITE has an active advisory council with robust representation of persons with developmental disabilities.

The Commission on Disability & Employment also addresses issues specific to developmental disabilities.

DOL is the lead agency for other collaborative entities such as the independent living and state rehab councils. While people with developmental disabilities may be represented in some capacity on these and other boards that focus on disability issues, intellectual disability and autism are not well represented, especially by self advocates or family members. Other boards with a broader focus (such as women's, elder issues, and including ADRCs) or workforce investment boards have representatives from the disability community, but this does not usually include persons with developmental disabilities or family members. Limited practical support is available for participating self advocates.

Other state agencies whose responsibilities include but are not specific to people with developmental disabilities (such as transportation, housing, and economic development) generally do not address issues specific to people with developmental disabilities, although they may address the broader disability community. And, while the state is paying increased attention to efforts to promote diversity, the focus is on race and ethnicity.

(v) Quality Assurance:

There are a variety of mechanisms in place to protect the rights of and monitor the quality of services for individuals with developmental disabilities.

The office of Child Protective Services, housed within Maine DHHS, responds to reports of abuse, neglect and mistreatment for all Maine children. There is an independent Ombudsman's office, which specializes in assisting people with resolving concerns and complaints with Child Protective Services. Otherwise, there are limited formal mechanisms for quality assurance for children's services. Monitoring requirements associated with previous consent decrees provided data regarding waitlists for children's services, but this information is no longer compiled. The Council receives anecdotal information from families having problems accessing needed services, but there are no reports availability to document the extent of the problem. DHHS has, however, assisted with collecting specific data, upon request.

Maine's P&A has taken a leadership role in assuring that clear specifications are adopted in rule for the appropriate use of restraint and seclusion in children's services, especially school settings. The Council is participating in a stakeholders' group which will propose adoption of new rules to provide clear direction on this issue.

There are two DHHS offices responsible for Adult Protective Services; one for people eligible for the ID/ASD waivers, and another for all others receiving adults' services. The separate office for ID/ASD waiver clients was developed in association with the Community Consent Decree. The DD Network is concerned about the use of community service provider agency staff as investigators for claims of abuse and neglect.

Adults with developmental disabilities who are not eligible for one of the ID/ASD HCBS waivers are served by the Adult Protective Services Office that addresses all other cases. Another ongoing concern voiced by advocates is that the 3 offices (CDS, Adult Protective for ID/ASD clients, and Adult Protective for all others) are functionally separate from one another, with separate databases that do not crosswalk with one another. This provides insufficient review for background checks, and is a pending issue to be resolved.

Quality Assurance for the HCBS waivers is the responsibility of DHHS staff. Maine has participated in the National Core Indicators project since 1999, and collects data through agency staff regarding service provision, and from families/guardians regarding satisfaction with services. The state agency has formed a new Council on Quality Improvement, to evaluate services provided under the two waivers. This council is not formalized in rule or statute at this time, and its potential impact is not yet measureable. The P&A took the lead in advocating for a statutory change in 2009 that increased the legal standard for court assignment of guardianship. There is continuing concern that public guardianship is currently the purview of the DHHS office that directs the HCBS waivers, with case managers also assigned responsibilities as guardian for some on their caseloads. Legislation in 2011 requested the Council convene a stakeholders' group which is developing recommendations to separate public guardianship from the state office responsible for service delivery

The DD Council supports leadership and self advocacy training through the Advocacy Day program and Disability Leadership Institute. Maine' self-advocacy organization, Speaking Up For US, participates in policymaking on a wide variety of topics and promotes efforts to increase opportunities for and effectiveness of self-determination, including offering an array of trainings for self-advocates across the state. There are more limited opportunities for leadership development and self determination among youth with developmental disabilities, in part because of limited access to adult services.

In addition, there are various interagency coordination efforts underway (described in Sect 3, Part B, iv Interagency Initiatives) that have goals of ultimately improving service quality

(vi) Education/Early Intervention:

Public education in Maine has been in turmoil in recent years. Controversy continues over a school district consolidation plan passed by the Legislature in 2009. While the number of districts has been reduced by nearly 100 from the original 270, debate over the plan continues. Meanwhile, Maine's budget deficits have resulted in reductions in state funds allocated to public education, while local communities complain about their increasing share.

Maine's total public school enrollment has dropped by 11% in the last 10 years, and the number of students receiving special education services is lower by 12%. Policymakers challenge the concurrent increase in costs for special education. However, child count data reveal a notable shift in numbers within individual special education categories that affect services needed and associated costs. During the last decade the numbers of students being served in the Specific Learning Disability and Speech/Language Impairment categories have dropped by 29% and 27%, respectively. Meanwhile, there has been a 272% increase in the number of students served in the autism category, many of whom are likely to require more services during the school day.

Early intervention services for children birth through 5 years of age are administered by the State Department of Education (DOE). The Child Development Services system has undergone substantial changes over the past few years, moving to a centralized administrative structure and reducing the number of regional sites from 15 to 9. There have also been shifts to a greater emphasis on use of a primary service provider model and a decrease in use of independent contractors.

A dramatic restructuring of Maine's Medicaid program in 2009 eliminated "developmental therapy" as a covered benefit, while adding/modifying other sections to clarify billable services and provider qualifications. DOE indicated in a report to the State Legislature in 2011 that these changes have resulted in a loss of Medicaid program funding for early intervention services of approximately $7 million, which has in turn required additional state dollars to pay for services in young children's educational plans. The changes have also complicated schools' ability to bill for medically necessary services that are provided in the school environment, with an associated loss in revenue to school districts of an estimated $30 million.

In 2008-2010, the interagency PDD Systems Change Initiative identified multiple service systems providing early identification and early intervention services, with redundancies and lack of coordination that can slow a family's access to services for their child. Multiple service plans and separate data systems are some of the issues to be addressed to make more efficient and effective use of resources to meet the needs of young children and their families. The division of administration and financing for early intervention programs between two separate state agencies resulted in a lawsuit and settlement agreement in 2008, and potential consolidation continues to be debated.

Stakeholders identify "transition services" as their primary concern related to older children with developmental disabilities. State rules require that schools begin transition planning for special education students when they enter high school, exceeding federal IDEA requirements. At the same time, however, the State Council on Transition and regional transition councils were disbanded in 2010; this action reinforced families' and advocates' concerns about the lack of coordination and support provided to facilitate youth with disabilities moving from school into adult services, post-secondary education and employment. This is exacerbated by the growing waiting lists for adult waiver programs for persons with intellectual disabilities and/or autism. For this reason, youth with significant disabilities may remain in the education system until age 21, in order to access other services and supports.

(vii) Housing:

Individuals with developmental disabilities and their families identify lack of affordable, accessible, integrated housing in their local communities as a significant problem. Some of the factors involved in this issue are shared with other populations in Maine. Persons with disabilities are disproportionately poor, and Maine's low-income population is in desperate need of affordable housing. Many individuals with developmental disabilities need accessible housing, which is limited in Maine's existing housing stock, in general some of the nation's oldest. Another issue is the proximity of employment options and community services and resources, given that many people with developmental disabilities do not own a vehicle or drive themselves. Access to any available public transportation system in the community is therefore also a consideration.

Housing is managed at the local level in Maine, with 26 separate local public housing authorities, and the state agency, Maine Housing, covering other geographic areas of the state. Affordable housing advocates list a number of issues to be resolved, including a lack of regional or statewide planning for affordable housing, uneven application and enforcement of building codes, and zoning restrictions on certain housing models. Advocates also point to increasingly restrictive state requirements for new housing developments which have resulted in a dramatic increase in costs and slowed project completion. In 2011 the Legislature created a Blue Ribbon Commission on Affordable Housing to review the status quo and recommend actions to maximize the investment of available resources and best meet the housing needs in Maine. Housing advocates are hopeful that the Commission's report in 2012 will result in policy changes that expand the availability of affordable housing across the state.

Individuals with developmental disabilities who do not qualify for one of the Medicaid waivers rely upon publicly-funded housing assistance programs, such as subsidized housing developments or Section 8. Concerns are raised about the inadequate supply of affordable, accessible housing, and the fact that subsidized housing developments may be "special purpose", limiting availability by age or disability type. These issues, along with the inadequate supply of individual Section 8 vouchers and attitudinal barriers that continue to affect access to rental housing for persons with developmental disabilities, limit available options. There are nearly 13,000 people on the waiting list for Section 8 housing vouchers across Maine, and the wait period can be several years. Some people with developmental disabilities are among the homeless population living in shelters across the state.

Most adults with developmental disabilities who receive Medicaid waiver services have housing and personal supports linked, with the agency or shared living provider owning or renting the residence. This limits the housing (and service) options for people with developmental disabilities in those programs. Many providers who offer residential services have received government subsidies for room and board costs of consumers they serve. These state-funded subsidies have been reduced in the past few years due to the fiscal crisis, and may be eliminated completely in the next state budget, due to continuing deficits. This situation creates significant challenges for service providers whose business models depend on that income stream. This in turn may impact the level and availability of services for persons with developmental disabilities.

With the creation of the community supports waiver, more adults with intellectual disabilities or autism are continuing to live with their families. They and their families are interested in identifying independent living options for the future, such as owning their own homes. This goal has been out of reach for most individuals with developmental disabilities in Maine, unless their families have significant resources and are able to provide the financial resources. However, there is growing interest in utilizing other sources of funding, including Section 8 vouchers, to finance home mortgage payments.

(viii) Transportation:

Maine is a rural state with limited public transportation options outside of the larger cities and towns. The cities of Portland, Bangor and Lewiston/Auburn provide frequent service along specific routes, along with complementary paratransit services. There are smaller systems in 12 other towns, which only operate Monday - Friday during daytime hours. There are also a limited number of transit providers that provide services once or twice a week in some rural areas of the state.

Most Maine residents rely on personal cars for transportation, but this is a significant expense for low-income populations, particularly with rising fuel costs. Individuals with developmental disabilities are disproportionately low-income, and many are unable to drive. Statewide lack of available, accessible, affordable and flexible transportation options, especially across county lines, during evening and weekend hours and for those with accessibility needs are significant barriers to employment and to full community inclusion for people with developmental disabilities. Paratransit services are provided in some areas, but are available only for medically necessary services, creating a barrier both to independent employment and basic community access. Other issues relate to the culture of automobile use that can result in support staff being unfamiliar or uncomfortable with and unable to teach the use of public transit. Families and support teams may also fail to consider transportation early enough in planning for housing, employment and services.

Most adults who receive services under one of the HCBS waivers have transportation provided by agency service providers. While transportation to a MaineCare-reimbursable service – whether a medical appointment or an employment site at which the person has a job coach funded by the waiver – is more easily delineated in an individual person-centered plan, there are concerns that provider rate cuts and high fuel costs are resulting in other access to community activities that further the goals of independence and community integration being restricted in ways that are difficult to monitor. Self-advocates report that they are not able to go out in the community as often, or they have to go with others from their group home without any choice of destination. There has been a notable reduction in attendance at some of the activities organized by Speaking Up for Us, and the Council has seen a drop in participation in the Advocacy Day program during the legislative session. However, quantitative and qualitative evaluation of the magnitude of this problem is a challenge.

Mainers with developmental disabilities who do not qualify for waiver services may be able to arrange for transportation through family or friends, but many rely on public and volunteer transportation through community agencies. Providers report that there are fewer volunteers available who are willing to provide transportation through community programs, due to the low mileage reimbursement rates.

The Council has participated in the Mainecare Advisory Subcommittee on transportation, whose charge is to identify problems and to make policy recommendations to improve access and quality. Based on recommendations of this committee, paratransit providers statewide have changed practices to increase access to same day transportation.

Transportation is one of the most frequently-raised issues by self-advocates and their families concerned about being able to work, and otherwise participate in their communities. However, broader solutions to address this major frustration for persons with developmental disabilities and their families have not yet been identified. The Council intends to invest in documenting any volunteer transportation networks that may exist in Maine and exploring opportunities for persons with developmental disabilities to be part of those networks, along with researching other options that may have been successful in other states with comparable geographic and resource challenges.

(ix) Child Care:

Not addressed.

(x) Recreation:

Not addressed.

PART C: Analysis of State Issues and Challenges [Section 124(c)(3)(C)]:

(i) Criteria for eligibility for services:

Maine's Medicaid program covers children whose families have incomes up to 200% of FPL. Maine also includes the Katie Beckett option in its State Plan. This option provides MaineCare eligibility for any child with significant disabilities that would otherwise qualify him/her for an institutional level of care. This Medicaid coverage and federal EPSDT requirements should result in children and youth being able to receive any "medically necessary" services they require. However, recent MaineCare program changes eliminated some services and restricted eligibility for specialized community support services to only those that are "evidence-based," which includes only Applied Behavioral Analysis for children with an autism spectrum disorders diagnosis at this time. This has resulted in some children not having access specialized services they need. And, while the "optional services" section of MaineCare should provide coverage pursuant to EPSDT requirements for "medically necessary" services not covered elsewhere under the State Plan, the approval process for this section is unclear and can seem arbitrary.

Maine has also tightened eligibility criteria recently for Katie Beckett and added a graduated monthly premium, which some parents find too high to pay. Given the limited availability of some services in the state, the loss of MaineCare eligibility is likely to make home/community-based supports inaccessible.

Early intervention services are available primarily through the Child Development Services (CDS) program overseen by the Maine Department of Education, and eligibility for these services is based on functional deficits documented through formal assessment. Recent narrowing of eligibility criteria has resulted in some young children with milder deficits not qualifying for services. Eligibility for extended school year services has also become more restrictive in recent years. A loss of MaineCare funding for CDS early intervention services has resulted in a significant budget deficit for this program, leading to discussions in the Legislature and the Executive Branch regarding ways to curtail expenditures. Advocates and families are concerned about potential changes in eligibility as a result.

Transition from school to adult services systems is likened by families to facing a "cliff." This is especially true for families whose children have had a combination of special education and home/community services funded by MaineCare, and are either found ineligible for adult services or put on a waiting list. Maine is one of a handful of states in which eligibility for adult home and community based services for persons with developmental disabilities requires a diagnosis of intellectual disabilities and an IQ of 70 or below or a diagnosis on the autism spectrum and a comparable level of functioning. Anyone who meets these criteria is entitled only to case mgmt services. The community supports waiver added in 2008 was to provide a second option for persons who could live with their families or independently. However, both the comprehensive waiver for those needing residential services and the smaller community supports waiver have been closed, with waiting lists that did not exist just 5 years ago now totally nearly 800 persons and continuing to grow.

Adults with developmental disabilities who have physical disabilities may be eligible for a self-directed personal services waiver, if found eligible for a nursing home level of care and able to/interested in managing their own services. However, this is a very small waiver and provides funding for limited service hours per week, which has eliminated this option for many individuals.

Eligibility for VR services is based on functional impairment and is the only adult service for which eligibility has not been identified as a concern. However, VR services are not provided to anyone who will need longterm job supports and is not covered by one of the HCBS waivers, effectively restricting access to job development services and work.

(ii) Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families:

One of the challenges is associated with Maine's limited experience with offering appropriate services for ethnic/cultural minority populations. The 5.6% of Maine's population that is non-white and/or Hispanic/Latino is comprised of very diverse and expanding groups. The Native American population is very small (only 1.3% are American Indian or of mixed heritage), but those living on the reservations in very rural areas of northern and eastern Maine have dramatically lower life expectancies. Extreme poverty is characteristic in those areas, and access to any services and supports is restricted, including for individuals with disabilities.

Another growing percentage is immigrants from Africa, the Caribbean and Latin America, based especially in two cities in southern Maine, which are federal refugee resettlement locations. The largest African group is the Somali population. Along with those that came directly to Maine, this is also the largest secondary resettlement location for Somali refugees in the U.S. Many African refugees have brought with them cultural beliefs that a child identified with a disability damages the prospects of all siblings, and brings shame to the mother. This cultural stigma complicates the language issues and other barriers to providing services. Refugee families are unlikely to even be aware of early intervention services, special education, etc. These and other minority groups have all been identified as having barriers (cultural, language, geographical or financial) that leave them unserved/underserved.

Maine's size and population density also present barriers. Most of Maine's population and wealth is concentrated in southern parts of the state. Those living in rural areas tend to be poorer, less educated, and have higher rates of health disparities. There are fewer choices of health care and service providers in rural Maine and less access to specialty care.

Another barrier to community participation which affects people with developmental disabilities across the state is ack of transportation to access activities and services. The winter snow and severe cold further complicate the travel distances in rural areas, but can also serve as barriers in cities and towns when sidewalks are not cleared or conditions make pedestrian as well as vehicle travel treacherous.

The limited categorical definition for eligibility for the home- and community-based waiver services program for persons with developmental disabilities leaves many others unserved or with inadequate/inappropriate services cobbled together through other programs. The requirement that an individual must have a diagnosis of intellectual disabilities with an IQ of 70 or below or an autism spectrum disorders diagnosis with a functioning level equivalent to IQ of 70 or lower, leaves many ineligible for these services. Persons with developmental disabilities who have a physical disability may qualify for the self-directed personal services waiver program, but may not be able to manage in a community living setting with the limited service hours per week the waiver has provided. Approximately 50 adults who have cerebral palsy, many in their 20's and 30's, have been identified living in nursing homes, due to the lack of supports that have been offered to allow them to live elsewhere. (A class action law suit is pending, and may result in a new waiver program that will allow this underserved population to move out of the nursing homes to community settings.) Others with physical disabilities are getting by without their needs met.

Adults who meet the federal definition of developmental disabilities who are not eligible for developmental disabilities services may receive limited assistance from other programs, which may or may not be appropriate to meet functional needs. Other adults with developmental disabilities do not receive services at all.

The Council has identified these unserved/underserved groups through public meetings, analysis of state data and services, and work with state agencies, as well as our sister developmental disabilities act organizations.

(iii) The availability of assistive technology:

Access to assistive technology in Maine is limited by availability of technology, cost, professional expertise, and environmental barriers.

For those who have identified assistive technology needs, but do not have the resources to obtain such items independently, there may be insurance coverage or funding through MaineCare. There is also a state loan program known as mPower, which is managed by the Finance Authority of Maine and offers low interest loans ranging from $250 to $100,000. The loan program also offers extended repayment periods to make them more affordable. Alpha One, the state independent living center, works with applicants for these loans to determine which adaptive equipment will best meet their needs. This loan program has made loans in excess of $8 million in the last 20 years. Loans are also available to businesses, to support modifications to work environments to make them more accessible and comply with ADA requirements.

The Maine Department of Education's Maine CITE Program, funded with a grant from the U.S. Rehab. Services Administration, is the statewide organization whose goal is to increase access to assistive and universally designed technology for persons of all ages. Maine CITE is not associated with any traditional service providers. Services are delivered through a partnership of private and public organizations that provide assistive technology demonstrations, equipment loans, alternative financing and public awareness.

Maine CITE works with programs supporting individuals across the lifespan, addressing needs connected to education, employment and community supports. The program has a dispersed geographic presence and partners with a variety of entities, including universities, the Center for Independent Living, Aging & Disability Resource Centers, and disability service providers.

Current priorities for Maine CITE include educating consumers about AT, supporting technology recycling, supporting the high demand for AT demonstration loan programs and the low interest loan program for adaptive equipment, as well as expanding access to universal technologies.

Areas of concern identified by Maine CITE, by Maine's P&A agency and through Council public forums include:

- Lack of availability of qualified AT professionals throughout the state and particularly in rural areas. Given that AT is a tiny fraction of the total caseload work of professionals, especially in rural areas, addressing this issue is more complex than providing training alone. Experience and practice are essential to developing a needed level of expertise. (This is further complicated by the lack of equipment available for hands-on evaluation.)
- Lack of availability of high speed internet service in parts of the state and low computer literacy among portions of the population affect consumers' ability to utilize some forms of assistive technology.
- Access issues related to high private insurance copayments and inadequate coverage for adaptive equipment.
- Lack of consensus as to what constitutes "medical necessity" for coverage under Maine's Medicaid program, especially pertaining to augmentative communication. Although DME is a required MaineCare service, the prior authorization process has been complex / burdensome; efforts to simplify it have not been successful to-date.
- Lack of back-up technology for equipment that malfunctions which can create significant problems for individuals dependent on these aids.
- Limited skills of support staff in working with technology, which can render the assistive device useless to the individual.
- Environmental barriers, such as weather, which can restrict use of assistive technology.

One positive development is that the state agency overseeing the broad-based home and community-based services waiver plans to include certain types of AT (to assist with monitoring safety and self-care) as a covered service in the next rewrite of the waiver.

(iv) Waiting Lists:

a. Numbers on Waiting Lists in the State:

Year	**State Pop. (100,000)**	**Total Served**	**Number Served per 100,000 state pop.**	**National Averaged served per 100,000**	**Total persons waiting for residential services needed in the next year as reported by the State, per 100,000**	**Total persons waiting for other services as reported by the State, per 100,000**
2011	13.280	2,803	211	142	37	32

b. Description of the State's wait-list definition, including the definitions for other wait lists in the chart above:

Eligibility criteria to be on waitlist for either of two 1915(c) HCBS waivers for adults with developmental disabilities: intellectual disability with IQ of 70 or below; or Autism Spectrum Disorder with equivalent functional impairments. A third 1915 (c) waiver is for self-directed services for adults eligible for nursing home level of care 18 yrs of age and older. (This includes persons with developmental disabilities, who have physical impairments, but also others with disabilities acquired after age 21.) Financial eligibility criteria must also have been met before a person is added to any of the lists - eligibility is up to 200% of FPL.

A 1915(c) HCBS waiver for children with intellectual disabilities and/or autism spectrum disorders began accepting individuals as of July 1, 2011. With a maximum of 40 children/youth to be served during the first year, a waitlist is expected - a child/youth at least 5 yrs old and under age 17 will be put on the waiting list if medical eligibility is met and child is in or need of institutional level of care (ICF or psych hospital).

c. To the extent possible, provide information about how the State selects individuals to be on the wait list:

Placement on any of the waiting lists is decided by Department of Health and Human Services staff, based on a determination of medical and level-of-care eligibility criteria, and verification of financial eligibility (for adults). The HCBS comprehensive services waiver waiting list has 3 groupings: Priority 1 is for persons in urgent need of residential services for health/safety reasons; Priority 2 is for those who are likely to need residential services within the next year; and Priority 3 includes those who may need residential services at a later future date. Individuals are also identified by date of eligibility, geographic location and age. Priority 1 list members are monitored for level of acuity and risk, and further triaged as openings on the waiver become available. Individuals are placed on the waiting list for the more limited Community Supports waiver in order of date found eligible; this is also the procedure for the self-directed physical disabilities waiver.

d. Entity who collects and maintains wait-list data in the State:

[ ] Case management authorities

[ ] Providers

[ ] Counties

[x] State Agencies

[ ] Other:

e. A state-wide standardized data collection system is in place:

[ ] Yes/No

f. Individuals on the wait list are receiving (select all that apply):

[x] No services

[x] Only case management services

[x] Inadequate services

[x] Comprehensive services but are waiting for preferred options (e.g., persons in nursing facilities, institutions, or large group homes waiting for HCBS)

[x] Other: Vocational Rehabilitation, Community Supports

Other services:

Vocational Rehabilitation, Community Supports

Other services description(s):

A person on the waitlist for the HCBS comprehensive services waiver is eligible for case management services and:

a) if under age 21 years and still in a public school program, may continue to receive Children's Services, including home/community supports, depending on level of need and availability of services, or services in an institutional setting (either an in-state PNMI or, in rare cases, out-of-state), when determined necessary;

b) may receive state-funded supports on a limited basis, if funds are available and needs are acute;

c) May currently be served under the Community Supports waiver, and receive a combination of employment supports and community/in-home supports, transportation services to access community activities, and limited respite funding,

d) May receive initial VR evaluation and job development services, especially if the person is receiving services under the Community Supports waiver, which will cover longterm job supports when needed;

e) Is likely to receive SSI or SSDI, and health care services covered by Medicaid, and may receive other income-based supports, A person on the waitlist for the HCBS community supports waiver is eligible to receive case management services and:

a) if under age 21 and still in a public school program, may continue to receive Children's Services, including home/community supports, depending on level of need and availability of services, or services in an institutional setting (either an in-state PNMI or, in rare cases, out-of-state), when determined necessary;

b) May receive VR evaluation and job development services, if longterm job supports are not needed,

c) Is likely to receive SSI or SSDI, and health care services covered by Medicaid, and may receive other income-based supports.

A person on the waitlist for the self-directed physical disabilities waiver may be in a nursing home, or doing without needed assistance, but likely has SSI/SSDI, Medicaid, and may receive other income-based supports.

g. Individuals on the wait list have gone through an eligibility and needs assessment:

[x] Yes

Comments for the above:

1) For the adult ID/ASD waivers, a person must meet diagnostic criteria for intellectual disabilities or autism spectrum disorders and need ICF/MR level of care, as measured using a CMS-approved tool. Also, for the comprehensive waiver, service needs are not projected to exceed 200% of ICF/MR costs; and for the community supports waiver, not to exceed 50% of ICF/MR costs. The state is in the early stages of adopting a resource allocation tool.

2) The Medical Eligibility Determination tool is administered by an outside contractor to determine eligibility for all other adult long term care services. To be determined eligible for the self-directed personal services waiver, an individual must also have the cognitive ability (as measured on the MED tool) and interest in self-directing services.

3) For the children's services waiver, qualified clinicians may use the Aberrant Behavior Checklist, Achenbach Behavior Checklist, Vineland Maladaptive Behavior Scale or Vineland to evaluate functional impairments and level of services needed.

h. There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g. person-centered planning services):

[x] Yes

i. Specify any other data or information related to wait lists:

There are few structured planning options for individuals or families waiting for services.

Children generally do not have long waits; depending upon age and medical status they often have access to care or case management which provides (limited) assistance with planning. There is no formal process in place to assure that older children and families receive adequate transition planning.

Adults eligible for either of the ID/ASD HCBS waiver are eligible for case management and person centered planning; in practice this is not effective without access to services.

Persons with developmental disabilities may require and not be receiving other types of supports (housing, respite, etc) that are not included in the waitlist count for "Other Services" for a variety of reasons (service does not exist, meaningful wait time data is not available).

Data regarding waitlists for children's services is much less comparable from year to year than that for adults, due to a variety of programmatic changes.

j. Summary of waiting list Issues and Challenges:

There is no systemic effort to share data among Maine Department of Education, DHHS Children's Services and Adults' Services programs, and Vocational Rehabilitation for budgeting and planning to assure resource availability and manage wait lists.

Access to either of the HCBS waivers for adults with ID/ASD has decreased significantly over the past 3 years; the wait list for the comprehensive HCBS waiver has increased by approx. 600%; the Community Supports waiver now has a wait list of nearly 300 people (no waitlist 3 years ago). This has disproportionately affected young adults exiting school. There has been a significant proportional increase in the number of young adults being found eligible for ID/ASD services (likely due at least in part to the dramatic increase in number of youth with autism spectrum diagnoses exiting school programs).

The new children's waiver program is expected to have a waitlist soon.

State budget difficulties are not expected to abate in the foreseeable future.

(v) Analysis of the adequacy of current resources and projected availability of future resources to fund services:

Maine's transition from a natural resources and manufacturing economy to a service-based economy has been difficult, and its dependence on tourism revenue has compounded the problem, given high fuel prices and other factors hat have negatively impacted the state. Maine also has the oldest population of any state and among the highest health care costs (adjusted for age and disability, as well as absolute). Serious concerns are raised by policymakers and advocates about how the needs of the state's aging population will be addressed, from both a fiscal and a workforce capacity.

Outside of the waiver programs for persons with ID/ASD, there is significant investment in and high use of institutions (nursing facilities) in long term care. While the general public overwhelmingly expresses its preference to receive support at home, there are significant systemic barriers to be overcome for the system to honor that preference, especially for those with significant functional needs. While ultimately home-based care is less costly, savings cannot be accrued in the near term.

And, while the overall school population is dropping, along with the aggregate number of special education students, there is a dramatic increase (over 300% in the last decade) in the number of students served in the autism category and other categories which are likely to include students with higher cost needs (e.g. multiple disabilities and mental retardation) remain constant. The adult services system is beginning to see the effect of this as well, with the HCBS waivers having growing waiting lists that did not exist three years ago.

Despite serious and persistent state budget issues and a radically altered state political climate, the state has continued to demonstrate a commitment to services for persons with developmental disabilities. In spite of the fiscal crisis, a small increase in funding was provided for the waiver programs in the last biennial budget, but this did little more than maintain existing levels of service. The comprehensive services waiver, in particular, has seen an increase in costs as those on the waiver develop age-related health complications. Meanwhile, there are a growing number of persons with high levels of support needs, many of them young adults, who cannot access waiver services. Rather than being able to utilize skills developed during school years, obtain gainful employment and otherwise contribute to their communities, these young people are going without services, with the resulting negative impact on them and their families.

The statistics and human stories clearly indicate a need for additional resources to assure that the needs of aging persons with ID/ASD who are receiving waiver services are met, as well as to address the numbers of young adults and their families who are or will soon be waiting for services. Yet, the current Administration has said it will address current needs within existing resources. This is predicated upon being able to significantly decrease the per person cost of services. However, one of the reasons that waiver costs are high is that the system has high rates of "residential placement": approximately 85% of waiver recipients live outside their family home, the majority in some type of group home. If the system is able to transition to a less expensive model of service, it could reduce per person costs. This is likely to be challenged by a provider network with high levels of investment in a residential infrastructure and a regulatory environment that is unprepared to address less traditional models of service. The Council anticipates that advocacy for resources needed to fund services and supports is likely to require more Council effort during the next 5 years than it has in the past, with a need to preserve individual choice and promote maximum independence, as well a community inclusion.

(vi) Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive:

The state makes extremely limited use of private ICFs (both residential and nursing), with about 200 residents served in these settings. These facilities tend to be somewhat larger than other group residences and the residents somewhat older. Because of the small population, there is little specific, meaningful data regarding satisfaction with this service. There have been attempts made to convert the remaining ICFs to waiver homes, and a few were converted in the past two years. This effort has not been successful with the remaining ICFs due to significant political opposition by providers and family members of residents.

A higher rate is paid for residential services in the ICFs, to cover the cost of medical staff. While the service model tends to be less individualized than others, reports indicate that services are generally safe and of reasonable quality. ICF residents may have less choice of health care providers (but do receive comprehensive health care) than do individuals living in community settings. The higher level of regulation in these facilities may also limit some types of everyday activities.

Institutionalized persons with developmental disabilities who do not qualify for ID/ASD waiver services are most likely to reside in general nursing facilities. Many are under 65. They are generally eligible for and may have used community services in the past. Others went into a NF from home as adolescents, when their families were no longer able to address their personal assistance needs. They reside in nursing facilities because they have not been able to move into the self-directed personal assistance waiver (which is very small and has a waiting list) or because they need the availability of personal assistance staff for more than the number of hours that is available through that waiver. Persons in NFs have access to health care, although they may have more limited choices than do people living in the community. They (generally) lack access to non-medical community transportation, to flexible and individualized supports, to privacy, and to opportunities for work or education. Anecdotal information from residents and family members indicates that these individuals may also receive a lower level of care in NFs (such as less frequent showers) due to the equipment and staff support needed to accomplish these tasks. A class action lawsuit was filed against the state in 2010 on behalf of approximately 40 adults with CP who are residing in NFs, alleging that they are not being provided services in the least restrictive environment and do not receive required active treatment. Settlement negotiations were underway as of the date of this plan.

It is likely that there are persons with developmental disabilities institutionalized in jails, prisons, or psychiatric facilities. The Council has anecdotal information raising questions as to whether these settings adequately meet the needs of persons with developmental disabilities. The Council expects that any future action to address this issue would be in collaboration with the P&A.

(vii) To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))):

For most of those that receive services, the comprehensive HCBS waiver provides a generally adequate level and quality of service. Systemic concerns about health and safety are not evident, nor are significant problems with satisfaction with services.

As measured nationally, service recipients have high measured levels of community inclusion, as well as relatively high levels of choice and control in everyday and life decisions. Services are rated as average in most areas: having adequate and satisfying relationships, access to/satisfaction with services (including health care), privacy, and employment. Services were rated as low in other areas: level of perceived safety in service environments and in their neighborhoods. The concern in service environments may be related to these commonly being group environments with others who may have challenging behaviors, but the nature of the neighborhood issue is unclear from the data collected. There is a high proportion of persons taking psychotropic medication, consistent with stakeholder reports and concerns. Self-direction was also rated very low, presumably due to the lack of a self-directed service option.

There are concerns about the adequacy of certain services under the comprehensive waiver, both anecdotal and as reported in unmet needs identified via the PCP process, particularly in the areas of dental care, housing, employment / community supports and provision of a volunteer correspondent. These concerns have increased with recent state budget pressures. It is not clear, however, to what extent this reflects an increase in need vs. improved reporting: it is likely that it is a combination of both. For example, access to dental services for persons living in poverty is known to be a long term, widespread problem worsened in recent years by Medicaid rate cuts and by fiscal challenges of organizations that have subsidized dental care. As this has happened, community support staff have also been actively encouraged to identify unmet needs.

There are very serious concerns about the adequacy of HCBS waiver services for all persons with developmental disabilities who need them. While Maine is not a "large wait list" state (yet), it is on track to become one as the wait list has grown by over 600% in less than 3 years. During the past year new recipients have been added to the waiver as vacancies occur (primarily due to age- or health-related deaths), but this has not kept pace with the growing number of those on the waitlist in Priority 1 status (at immediate risk for health/safety).

This difficult reality becomes more grim when one considers the extremely narrow eligibility criteria for the ID/ASD waiver program and the significant percentage of persons with developmental disabilities who are not eligible for either of the waiver programs, and are not able to access needed services and supports.

Those adults with developmental disabilities who receive community-based services via the Physical Disabilities Waiver, particularly the most vulnerable, may be inadequately served and at risk of institutionalization. The low caps on services, the difficulty in recruiting and retaining personal assistance staff (which is the responsibility of the individual waiver recipient), and the lack of any system for assuring back-up support staff can leave individuals in life-threatening situations. Safety concerns can lead to institutional placement.

The addition of a children's waiver to provide home- and community-based services for children with ID/ASD and complex needs in 2011 is expected to provide the capacity to meet the needs of children who have had to be placed in institutional care, some of which are out-of-state. Given the strong concerns expressed by families and state data that documents the growth in numbers of children with autism spectrum disorders, it does not appear that the waiver will be available to all children and their families in need of this level of support.

PART D: Rationale for Goal Selection [Section 124(c)(3)(E)]:

Goals were developed in several drafts in direct response to public and stakeholder input, staff research and analysis, and informed by the mission and values of the council through member participation. Special emphasis was paid to input of self advocate/parent members; current Council activities were not considered (except as how they fit as objectives in the new plan). The plan was developed in a climate of and with the expectation of ongoing budgetary challenges.

Specific goals identified are:

1. Access to Services was identified as a concern for persons with developmental disabilities from cradle to grave, with increasing urgency in light of the difficult fiscal situation. Despite legal requirements, children with developmental disabilities have difficulty accessing supports that prepare them to contribute as adults. Young adults with developmental disabilities are disproportionately un/underserved. Disparities continue to exist in health and employment status. Little planning has taken place for the needs of the growing cohort of aging adults with developmental disabilities. Those with developmental disabilities without intellectual disabilities receive limited support and are at risk of institutionalization.

2. Self Advocacy activities have long been reported to the Council as among its most important and effective endeavors. While Maine has a well-established self advocacy organization, it is critical to broaden the base of support (political, financial, and practical), as well as to expand the role of self advocates (representing the full spectrum of developmental disabilities) and the variety/scope of issues of concern, in order to achieve the Council's long term vision.

3. Self Determination: The Council heard clearly from self-advocates and family members about their objections to the current situation in which the choice and control of many persons with developmental disabilities and their families for support with critical aspects of life (from housing to personal assistance to employment) is proscribed by systemic limitations. The Council is particularly concerned about youth in transition, i.e feedback collected that pointed to the

lack of timely information and use of guardianship as a "rite of passage," as well as the lack of self-directed service options for persons of any age with intellectual disabilities.

4. While Valued Community Membership may be presumed to be an outcome of the other goals, the Council and others providing input to the development of the plan discussed the need to change community perceptions in order to open more opportunities for persons with developmental disabilities to be truly included and supported in their individual right to self-determination. The Council felt that it was critical to address this on its own due to overwhelming input and experience that this continues to be out of reach for many, even those receiving ostensibly high quality services. Persons with developmental disabilities experience high rates of unemployment and social isolation (suggesting that they are not well integrated into such common roles such as employee, neighbor and friend).

Far more problem areas were identified than the Council has corresponding resources to address. The Council therefore weighed all of the issues raised in the context of the systemic change activities that are its purview, and those items that may follow as later priorities to build on successful completion of the objectives and activities ultimately selected. The Council examined all of the issues identified throughout the planning process in light of the state and federal fiscal and policy arena, and in particular by focusing and refocusing on the experiences and expressed desires of self-advocates and family members. The Council also recognized that this Plan will not exist in a vacuum, but must instead be re-evaluated on an ongoing basis to assure that the Council can adjust its targets and activities as necessary to accommodate unforeseen developments/changes in the environment in which this Plan is being implemented.

PART E: Collaboration [Section 124(c)(3)(D)]

(i) As a Network:

During the next 5 years, the Maine DD Network will continue to collaborate in a variety of ways to address shared priorities. A primary area of collaboration is in supporting the statewide self-advocates' organization, Speaking Up for Us. The Council provides funding and other types of assistance to SUFU, along with the P&A and the UCEDD, to strengthen the organization's structural and membership base, and to engage SUFU in public policymaking activities, along with broader engagement in local communities across Maine. The DD Network in Maine includes SUFU as a partner, and will together work with SUFU to further the goals and address issues identified at the Allies in Self-Advocacy Summit in May, 2011.

In addition, the DD Network will continue to focus on improving the employment rate for persons with developmental disabilities, with each partner addressing an integral component of this effort. The Network will follow up on a jointly-sponsored seminar and training in September 2011 to promote stronger advocacy for employment opportunities for persons with developmental disabilities by including newly-trained employment advocates in legislative advocacy and public education activities, while the UCEDD will continue educational outreach efforts to increase knowledge and understanding of appropriate inclusion and support for persons with developmental disabilities, especially ASD, in employment settings. Per agreement at the Summit, the Network will continue to develop additional collaborative efforts to address this issue.

The Network will also work together to identify potential ways to improve the availability of transportation services for self-advocates in Maine.

In addition, the network will continue to collaborate through their participation in activities of the Dual Diagnosis Task Force to address issues related to access to quality mental health care for persons with developmental disabilities.

(ii) With each other: **(e.g. Describe the plans the Council has to collaborate with the UCEDD(s). Describe the plans the Council has to collaborate with the P&A.)**

In collaboration with the UCEDD the Council will, among other activities, do the following:

a) Support outreach efforts regarding integrated childcare, and support for families and providers to enable young children with disabilities to be included in daycare settings with their peers who do not have disabilities, by sharing informational materials and links to training opportunities through the UCEDD. Disseminate materials and support outreach efforts regarding integrated childcare.

b) Collaborate with UCEDD staff in addressing strategic plan developed as part of the Act Early project, and other activities to expand availability of quality services for young children with disabilities.

In collaboration with the P&A, the Council will, among other activities, do the following:

a) Develop and act on a public policy advocacy agenda to address critical issues affecting children and adults with developmental disabilities, including legislation to adopt rules related to use of restraint and seclusion in schools; increases in funding to address the growing waiting lists for adult services; redesign of adult developmental disabilities services to separate public guardianship responsibilities from the state office providing case management services; adoption and implementation of state policies that promote employment for persons with developmental disabilities in inclusive, integrated environments; and restructuring of adult protective services data systems to ensure linkages and sharing of information.

b) Coordinate the Maine Education Advocacy Alliance to involve multiple organizations focused on children with disabilities and their families in collaborative advocacy efforts related to early intervention, special education and transition services.

(iii) With other entities: **(e.g. network collaboration with other entities in the State, including both disability and non-disability organizations, as well as the State agency responsible for developmental disabilities services)**

The Council maintains an email network with other organizations that address issues through their programs and advocacy that impact on persons with developmental disabilities. When the State Legislature is in session, the Council publishes a weekly update on all legislation affecting persons with disabilities. The Council will collaborate with others in this network to provide information to public policymakers at the state and national level regarding key issues. In addition, the Council members and staff will participate in a wide range of stakeholder groups to provide input to policymaking activities, including the MaineCare Advisory Committee; the Maine Advisory Committee for the Education of Children with Disabilities (I.C.C. for IDEA Parts B and C); and the State Commission on Disability & Employment.

The Council will continue to convene working groups at the request of the State Legislature to address specific topics. In FY12, the Council will facilitate presentation of reports to the Legislature from stakeholders' groups examining public guardianship responsibilities, and evaluation of DD Services oversight/advisory functions assigned to several federally- and state-funded entities. The Council will also submit draft legislation based on collaborative work with Maine DHHS and the State Code Revisor's Office to eliminate the term "MR" from all state statutes, per request of the Legislature.

The Council will continue to collaborate with Maine DHHS and other DD Network agencies, to support Speaking Up For Us. In addition, the Council will collaborate with Maine DHHS and others in FY12 to co-host a state conference for parents of adults with developmental disabilities, to provide information on a wide range of topics and encourage the development of a more organized parent/sibling network to represent the concerns of families of adults with developmental disabilities, and advocate for public policies/funding that facilitate self-determination, community inclusion and maintenance of necessary services for persons with developmental disabilities and their supporters.

Section IV: 5-Year Goals [Section 124(4); Section 125(c)(5) and (c)(7)]

GOAL # 1: Access to Quality Comprehensive Services and Supports

MDDC will support self-advocates, families and stakeholders in advocacy, capacity building and systems change activities that result in individuals with developmental disabilities being able to access quality comprehensive services and supports that enable them to participate in community life as they choose.

Areas of Emphasis:

[x] Quality Assurance

[x] Education and Early Intervention

[x] Child Care

[x] Health

[x] Employment

[x] Housing

[x] Transportation

[x] Recreation

[x] Formal and Informal Community Supports

Strategies to be used in achieving this goal:

[x] Outreach

[x] Training

[ ] Technical Assistance

[x] Supporting and Educating Communities

[x] Interagency Collaboration and Coordination

[x] Coordination with related Councils, Committees and Programs

[x] Barrier Elimination

[x] Systems Design and Redesign

[x] Coalition Development and Citizen Participation

[x] Informing Policymakers

[x] Demonstration of New Approaches to Services and Supports

[ ] Other Activities

Objectives/Implementation Activities/Timeline:

Objectives	Implementation Activates	Timeline
Support three initiatives to improve access to quality mental health services for persons with DD by expanding the pool of professionals with specific training in dual diagnosis, and decreasing barriers to accessing quality, timely services.	1. Conduct & support three Dual Diagnosis Task Force meetings in FY 12 & prepare final report/recommendations to state agency for future collaboration between service systems. 2. Collaborate with partners to develop & distribute informational material regarding appropriate services/supports to address mental health needs of persons with DD through at least two family organizations & the statewide self-advocates' organization. 3. Identify & advocate for at least two potential changes to current policies (statutes and/or rules) related to MH/DD services which would resolve systemic barriers to quality services. 4. Monitor implementation of new training curriculum for direct support	Year One – support task force & provide funding for trainings (9 months); development of informational materials for families & self-advocates thru collaboration with pertinent stakeholder groups (by end of FY12) Year Two: arrange for distribution of informational materials to self-advocates & families; Ongoing– collaboration with advocacy partners to monitor & provide input to

	providers & effectiveness of training through follow-up survey of DSPs trained. 5. Support the development, sustainability & availability of at least two training resources for service providers, clinicians & case managers.	policy-making activities affecting availability & quality of mental health services for persons with DD
Engage with at least three other partners to remove barriers to expanded implementation of the "medical home" model and provision of coordinated and effective cross-disciplinary services for children with developmental disabilities.	1. Conduct pilot project re use of medical home model to coordinate services for young children with ASD & other DD, & provide information regarding project findings to policymakers. 2. Promote development of consolidated planning process for young children with DD. 3. Support provision of training & tech. assistance to primary care providers to promote children with DD receiving ongoing care management thru primary care medical home. 4. Participate in advisory & oversight efforts to improve the state's Medicaid program capacity for addressing the needs of children with developmental disabilities & assuring that EPSDT requirements are met.	Year One - conduct pilot project re medical home model. Year Two - analyze results of pilot project and develop recommendations for systemic changes. Year Two - present findings and recommendations to policymakers. Ongoing - participate in monthly Medicaid Advisory Committee meetings & rule-making activities. Ongoing - work with other stakeholders & policymakers to address systemic barriers to effective, coordinated services.
Engage in three or more cross-disciplinary initiatives to remove barriers to early identification and access to timely and well-coordinated early intervention services for young children with developmental delays and	1. Promote & expand screening for ASDs & other DD in young children thru training of early childhood service providers, & Grand Rounds presentations for physicians. 2. Conduct pilot project re communication between Child Development Services and developmental pediatricians to expedite evaluation & access to services, & provide information regarding project findings to policymakers. 3. Monitor implementation of Early Intervention & autism health	Year 1: conduct trainings for early childhood providers, Grand Rounds presentations. Year 1: conduct pilot project re CDS/physician collaboration. Year 1-3: monitor implementation of insurance statutes re coverage for early intervention for children with DD, & coverage specific to children with ASD.

disabilities.	insurance statutes. 4. Collaborate with other stakeholders to provide information to families regarding health insurance changes & coverage for services for young children with disabilities. 5. Participate in the Maine Advisory Committee for the Education of Children with Disabilities, the advisory committee to the Department of Education regarding early intervention & special education services. 6. Participate in the Medicaid Advisory Committee regarding development & modification of regulations & provide information for policymakers.	Year 1: support distribution of information for families re health insurance coverages. Ongoing: participation in state advisory committees & provide information for policymakers.
Expand access to quality health care services for persons with developmental disabilities and their families by engaging in at least four initiatives that result in increased numbers of medical care providers who have received training and expanded their capacity to address health care needs of children and adults with developmental disabilities.	1. Conduct focus groups with families and medical providers to identify barriers to youth transitioning from pediatric to adult medical care. 2. Provide support for development & provision of outreach & education to rural health care providers to support their efforts to provide accessible & effective services for persons with DD. 3. Support development & distribution of informational materials for primary care providers regarding services & supports for children with DD, including differentiation between "medical necessity" & "educational need" as those terms relate to funding streams to cover cost of care. 4. Support the development of distance learning opportunities related to DD. 5. Support & promote the use & expansion of telemedicine in providing appropriate & effective medical services for persons with DD. 6. Advocate for expanded access to community dental care for persons with DD.	Year One: conduct focus groups & compile findings. Year Two: support development of information/training to support transition from pediatric to adult medical care Year One: support development & distribution of information for medical care providers re services/supports & funding streams to cover services. Year One: support development of curricula for distance learning opportunities for medical providers. Ongoing: provide input to policymakers re systemic barriers to quality care.

Support at least three cross-systems initiatives to increase access to appropriate and effective services and supports for adults with developmental disabilities and dementia-related conditions.	1. Participate in policymaking activities regarding services for persons with dementia-related conditions to assure that the needs of people with DD are formally addressed. 2. Support efforts to increase awareness & identification of Alzheimer's disease & other dementia-related conditions among people with DD and their families. 3. Support efforts to identify & disseminate best practices regarding services & supports for dementia among people with developmental disabilities.	Year 1: Participate in stakeholders' group to develop "State Alzheimer's Plan." Year 2: Support development of resource info for self-advocates & families re ID & treatment of dementia-related conditions in individuals with DD. Year 2: Participate in working group to identify & distribute info re "best practices" re services/supports. Year 3: Support distribution of information/training for self-advocates & families.
Provide opportunities for at least 200 state-level policymakers in the executive and legislative branches to learn about the needs of un-served and under-served individuals with developmental disabilities and their families and about key components of quality services that support self-determination and community inclusion.	1. Develop public awareness materials regarding services & supports that enable persons with DD to have self-determined lives in their local communities & materials regarding the growing waiting lists for services. 2. Prepare & provide annual reports & other educational materials to state legislators & other public policy makers regarding the current capacity of funded state programs to meet the needs of persons with DD. 3. Provide information to public policymakers that will support their acknowledgment of the principles of self-determination & community inclusion in decisions affecting services & supports for persons with DD.	Year 1: Collaborate with partners to develop public awareness materials Year 1: October thru February: prepare & present report to Legislature's Health & Human Svs. Committee re Council role, activities and issues of concern. Annually in January: prepare & present to Governor, Legislature & Cong. delegation report re status of persons with DD and their families in Maine, especially waiting lists & unmet needs. Ongoing: Support self-advocates & families to contact policymakers.

Engage in at least three activities that support a 10% gain in positive employment outcomes for adults with developmental disabilities.	1. Advocate for policies that support persons with DD attaining & advancing in integrated community employment. 2. Collaborate with partners to advocate for policy & practice changes needed to increase access to vocational training, employment services & supports. 3. Support efforts to educate communities about the contributions & potential contributions of persons with DD as employees. 4. Participate in the Alliance for Full Participation Summit & share with stakeholders. 5. Promote efforts to improve communication & collaboration between case managers & vocational rehabilitation counselors.	Year 1: Participate in Alliance for Full Participation & follow-up activities in Maine. Year 1: Develop public awareness materials re integrated employment
Address at least five policy, practice and/or funding barriers to assure an increase in the availability and/or quality of education programs, community services and natural supports for individuals with developmental disabilities and families.	1. Advocate for policies/statutes that assure effective use of resources & provide comprehensive oversight of services for persons with DD. 2. Participate in finalization of Shared Living Program redesign & monitor implementation. 3. Participate with the Maine Emergency Mgmt. Agency to develop & maintain local capacity to address the needs of persons with disabilities in emergency situations. 4. Promote expanded training options for teachers/paraprofessionals working with children with ASD. 5. Advocate for appropriate services in all state longterm care programs, to assure the distinct habilitation needs of persons with DD are met & to promote expanded opportunities for independence & community inclusion. 6. Continue to coordinate the Maine Education Advocacy Alliance, &	Year 1 – lead stakeholders' group to clarify oversight duties; prepare comprehensive report re services & needs for Legislature; finalization of Shared Living; advocacy re longterm care restructuring; seclusion & restraints rulemaking for special education. Year 2 – continue oversight responsibilities, monitoring & advocacy role related to longterm care services program restructuring; work with ADRCs. Ongoing: continue work with MEMA, MEAA; oversight of DD services

	maintain an active role in policymaking activities affecting students receiving special education services. 7. Identify areas for improved communication & collaboration with Aging & Disability Resource Centers.	
Support at least two initiatives that increase the number of individuals with developmental disabilities who have access to self-directed, individualized housing and participation in activities in their communities of choice.	1. Develop & promote a policy statement addressing self-determination & the economic realities of people with developmental disabilities that reflect a need for long-term housing support separate from community supports. 2. Support the provision of education & support to stakeholders regarding best practice for long-term affordable housing independent of services. 3. Support the development & provision of informational materials regarding long-term affordable housing options for persons with DD to be available to families & individuals with DD. 4. Participate in efforts to examine systemic barriers to the provision of affordable housing options to persons with DD. 5. Advocate for self-directed services options in children's and adults' services.	Year 1: develop policy statement; collaborate to offer housing conference for parents/self-advocates; draft informational materials Year 2: modify Council website to incorporate webpage with housing resources, training Ongoing: advocacy to remove barriers to affordable housing, & addition of self-directed services options.

Intermediaries/Collaborators Planned for this goal (if known):

[x] State Protection and Advocacy System
[x] University Center(s)
[x] State DD Agency
Maine Parent Federation
Speaking Up For Us of Maine
Maine Primary Care Association
Maine Chapter, Amer. Academy of Pediatrics
Maine Equal Justice Partners
Autism Society of Maine
Learning Disabilities Association of Maine
Maine Department of Education
Maine Department of Labor
HeadStart
Developmental Pediatricians
Alzheimer's Association of Maine
Elder Issues Partnership
Child Development Services providers

GOAL # 2: Self-Determination

MDDC will engage in advocacy, capacity building and systems change activities so that Maine residents with developmental disabilities and their families will be able to exercise self-determination by exercising choice and control, and directing their own services.

Areas of Emphasis:

- **[x] Quality Assurance**
- **[x] Education and Early Intervention**
- [ ] Child Care
- **[x] Health**
- **[x] Employment**
- **[x] Housing**
- **[x] Transportation**
- **[x] Recreation**
- **[x] Formal and Informal Community Supports**

Strategies to be used in achieving this goal:

- **[x] Outreach**
- **[x] Training**
- [ ] Technical Assistance
- **[x] Supporting and Educating Communities**
- **[x] Interagency Collaboration and Coordination**
- **[x] Coordination with related Councils, Committees and Programs**
- [ ] Barrier Elimination
- **[x] Systems Design and Redesign**
- **[x] Coalition Development and Citizen Participation**
- **[x] Informing Policymakers**
- [ ] Demonstration of New Approaches to Services and Supports
- [ ] Other Activities

Objectives/Implementation Activities/Timeline:

Objectives	Implementation Activities	Timeline
Engage in initiatives addressing four or more lifespan transitional phases or events that result in at least 500 individuals with developmental disabilities having improved access to adequate, timely and effective transitional services and supports.	1. Support the development of interagency collaboration between the Child Development Services program & public schools to facilitate improved transition to public school programs from early intervention services. 2. Promote development & evaluate effectiveness of interagency MOU addressing transition services & interagency coordination of services. 3. Promote efforts to improve communication & collaboration between case managers, VR counselors, schools and families. 4. Support development & provision of informational materials regarding long-term affordable housing options for persons with DD to be available to families & individuals with DD. 5. Support outreach efforts to provide info for persons with DD & their families about systems & services. 6. Support efforts to increase opportunities for early work experience for youth with developmental disabilities. 7. Promote availability & use of holistic person-centered (comprehensive futures) planning for individuals with DD.	Year 1-2: Participate with other Maine Education Advocacy Coalition members in advocating for improved transitional services & support from early intervention programs to school. Year 1: Advocate for policy changes to clarify and improve transition services. Year 1: Contract for development of informational materials regarding affordable housing options. Ongoing: Support outreach activities of statewide self-advocacy organization. Year 2: develop plan for specific efforts for #6 & #7.

Provide opportunities for at least 200 individuals with developmental disabilities, families and stakeholders to learn about civil rights and less restrictive guardianship options.	1. Convene & participate in a task force to develop a plan for transferring responsibility for public guardianship to an entity independent of the state agency that provides case management. 2. Support the development & provision of training regarding guardianship options for individuals with DD & families. 3. Support outreach & training programs of the statewide self-advocacy organization, Speaking Up For Us, regarding civil rights & guardianship options.	Year 1: Convene & provide support to stakeholders' group Year 1-2: Participate in policy change activities re agency responsible for public guardianship Year 2-3: Support development, field testing & finalization of resource materials for individuals with DD & families re guardianship options. Year 3 and ongoing: Promote availability of information regarding guardianship options for families & self-advocates. Ongoing: Provide support for Speaking Up for Us activities.
Support the involvement of at least 100 individuals with developmental disabilities & family members in leadership & policy making roles to address at least five areas of concern identified by self-advocates & their families that impede individual choice & management of services & supports.	1. Facilitate & participate in the Maine Education Advocacy Coalition. 2. Provide Consumer Empowerment grants to individuals with DD & family members to facilitate participation in educational activities that expand their capacity to participate in policy-making activities. 3. Provide financial & other support to the statewide self-advocacy organization, Speaking Up For Us. 4. Support development & implementation of outreach strategies to inform individuals & families with information about range of options for services & supports, & individual choice & control opportunities. 5. Advocate for service models that allow people to direct their own services. 6. Advocate for policies & practices in government agencies & community service provider agencies that result in information being available to families & individuals with DD regarding the range of service options they may choose.	Year 1: Participate in stakeholder group to examine oversight & advisory functions of federally-mandated DD entities (DD Council, P&A) and others, to assure coordination, effective use of resources, & avoid gaps in oversight activities. Ongoing: Support involvement of self-advocates & family members through funding for Speaking Up for Us and Consumer Empowerment grants. Ongoing: other activities, with Council establishing priority efforts dependent upon pending public policy issues.

Intermediaries/Collaborators Planned for this goal (if known):

[x] State Protection and Advocacy System

[x] University Center(s)

[x] State DD Agency

Speaking Up For Us

Parent Advocacy organizations

Maine Association of Community Services Providers

Maine Department of Education

GOAL # 3: Self-Advocacy

MDDC will collaborate with the statewide self-advocacy organization and other stakeholders to increase the participation of self-advocates in policymaking activities in leadership roles.

Areas of Emphasis:

[x] Quality Assurance
[ ] Education and Early Intervention
[ ] Child Care
[ ] Health
[ ] Employment
[ ] Housing
[ ] Transportation
[ ] Recreation
[ ] Formal and Informal Community Supports

Strategies to be used in achieving this goal:

[x] Outreach
[x] Training
[x] Technical Assistance
[ ] Supporting and Educating Communities
[x] Interagency Collaboration and Coordination
[ ] Coordination with related Councils, Committees and Programs
[ ] Barrier Elimination
[ ] Systems Design and Redesign
[x] Coalition Development and Citizen Participation
[x] Informing Policymakers
[ ] Demonstration of New Approaches to Services and Supports
[ ] Other Activities

Objectives/Implementation Activities/Timeline:

Objectives	Implementation Activates	Timeline
Increase by 50 the number of individuals with developmental disabilities and their families who have received comprehensive advocacy training in leadership, public policy development and self-determination, and are engaged in systems advocacy activities	1. Provide comprehensive advocacy training available to individuals with DD & their families through the two-year Disability Leadership Institute. a) Conduct statewide recruitment for participants. b) Conduct six weekend trainings in first year c) Oversee & provide technical assistance to participants working on individual projects in Year 2. d) Maintain ongoing contact with graduates to engage 2. Investigate the potential benefits & cost of piloting Youth Leadership Forum	Year 1: Graduation of FY09-11 DLI class. Year 1: Conduct six weekend trainings for next DLI class Address objective 1; new DLI class of 16 Year Two: Address objective 2 Year Three: Address objective 1; new DLI class of 16 Year Four: Year Five: Address objective 1; new DLI class of 16
Provide opportunities for at least 400 individuals with developmental disabilities, family members and supporters to be engaged in advocacy activities with state and federal policymakers regarding issues of interest to the developmental disabilities community.	1. Support outreach & training programs of the statewide self-advocacy organization, Speaking Up For Us. 2. Make comprehensive advocacy training available to individuals with DD & their families through the Disability Leadership Institute. 3. Provide support to self-advocates, family members & supporters in engaging with elected officials through the Advocacy Day program & associated community visits with legislators. 4. Facilitate & participate in public policymaking activities that	Year 1: collaborate with Code Revisor's office & DHHS to develop draft legislation to remove disrespectful labels, & shepherd bill thru process; coordinate stakeholder group to review oversight responsibilities & prepare report to Legislature. Annually: conduct Advocacy Day program during Legislative session, & assist self-advocacy org. in organizing community visits. Ongoing: Conduct Disability Leadership

	result in the elimination of disrespectful labels related to persons with disabilities from state statutes & rules. 5. Participate with other stakeholders in advisory & oversight activities related to services for children & adults with DD.	program Ongoing: provide support to Speaking Up For Us.
Support new opportunities for individuals with developmental disabilities to engage in leadership and policy making roles in at least five cross-disability and policymaking entities affecting rights of/services for individuals with developmental disabilities and their families and through participation in five policymaking entities focused on general community issues.	1. Provide financial & other support to the statewide self-advocacy organization, Speaking Up For Us. 2. Identify potential areas for expanded involvement of youth with developmental disabilities in providing input to state service systems, & advocate for outreach to this population. 3. Promote the involvement of people with DD & their families in community decision-making through membership on local boards, commissions & other governing bodies in such areas as transportation, emergency management & public health.	Ongoing: support for statewide self-advocacy organization. Year One: investigate options for increased engagement of youth with DD & develop plan for activities beginning in Year 2. Ongoing: share information via public media, social media & communications with Council email list, as well as through other organizations regarding opportunities to participate in community & state-level policymaking boards & groups.
Support a 100% increase in paid and active members in the statewide self-advocacy organization, Speaking Up For Us, and an expanded role for the organization at the local and state level in public policy advocacy activities.	1. Assist Speaking Up for Us in the development & implementation of a membership campaign that results in additional support available to the organization & assures that the organization is responsible to the diverse needs of the DD community. 2. Provide support to self-advocates, family members & supporters in engaging with elected officials through the	Year 1: provide support for Speaking Up for Us to develop & implement membership campaign Annually, during legislative session: Offer bi-weekly Advocacy Day program & provide assistance to Speaking Up For Us in preparing/presenting information to

	Advocacy Day program & associated community visits with legislators. 3. Support the identification of community supports to enable the development of additional local chapters of the statewide self-advocates' organization.	policymakers. Ongoing: provide ongoing funding & technical assistance to Speaking Up For Us to support development of new local chapters & community involvement in providing informal support for chapter activities.
Increase engagement of families of adults with developmental disabilities in advocacy by supporting the development of a statewide family advocacy organization with membership of at least 100.	1. Collaborate in presenting one or more state/regional events for parents & siblings of adults with DD annually. 2. Provide support for development of a statewide network/organization to strengthen the advocacy capacity of families. 3. Support the development & provision of training regarding guardianship options for individuals with DD & families (as detailed under Goal 1). 4. Investigate opportunities for peer support for families of youth with developmental disabilities in navigating transition from education & children's services to employment, adult service systems & community living.	Year 1: Provide support for efforts to develop statewide advocacy organization for family members of adults with DD Annually: Work with other stakeholders to conduct state/regional event(s) for parents & siblings. Year 2: Evaluate options for peer support networks for families of youth in transition phase & determine strategic investment to expand availability of this resource. Year 3: Implement strategy developed to address peer support for families.

Intermediaries/Collaborators Planned for this goal (if known):

[x] State Protection and Advocacy System

[x] University Center(s)

[x] State DD Agency

Speaking Up For Us
Maine Parent Federation
The National Arc
Autism Society of Maine

GOAL # 4: Opportunities for Inclusion as Valued Members of Communities

MDDC will engage in advocacy, capacity building and systems change activities to effect change that results in persons with developmental disabilities and their families having equal opportunities to be included as visible, active and valued members of their communities.

Areas of Emphasis:

[x] Quality Assurance
[ ] Education and Early Intervention
[ ] Child Care
[ ] Health
[ ] Employment
[ ] Housing
[ ] Transportation
[x] Recreation
[x] Formal and Informal Community Supports

Strategies to be used in achieving this goal:

[x] Outreach
[x] Training
[ ] Technical Assistance
[x] Supporting and Educating Communities
[ ] Interagency Collaboration and Coordination
[x] Coordination with related Councils, Committees and Programs
[ ] Barrier Elimination
[ ] Systems Design and Redesign
[x] Coalition Development and Citizen Participation
[ ] Informing Policymakers
[x] Demonstration of New Approaches to Services and Supports
[ ] Other Activities

Objectives/Implementation Activities/Timeline:

Objectives	Implementation Activities	Timeline
Resolve at least three policies and/or practices to remove systemic barriers and expand opportunities for individuals with developmental disabilities to be integrated members of Maine's workforce and to have increased access to individualized vocational training, education, self-employment and customized employment.	1. Participate in the Alliance for Full Participation Summit with other Maine stakeholders 2. Collaborate with other stakeholders to advocate for Employment First policy for Maine. 3. Monitor statewide data regarding the comparative costs & employment outcomes of state-funded employment supports. 4. Provide information to the State Legislature regarding the employment status of individuals with developmental disabilities. 5. Participate in initiatives to expand access to integrated employment opportunities for persons with DD. 6. Participate as a member of the Maine Commission on Disability & Employment. 7. Support the statewide self-advocacy organization in providing peer-to-peer information about integrated employment opportunities and community participation. 8. Collaborate with parent organizations to promote integrated employment as a future goal for children with developmental disabilities.	Year 1: Participate in AFP Summit Year 1 & 2: Collaborate with other stakeholders to develop/implement strategic plan to promote & advocate for Employment First policy for Maine. Years 2-5: Collaborate with Speaking Up for Us & parent organizations to educate self-advocates & parents of children with DD about integrated employment as a goal & employment options. Annually: provide info re employment for persons with DD to Legislature. Monthly: participate in Commission on Dis & Emp. meeting
Provide opportunities for at least 100 legislators or policymakers	1. Collaborate with other stakeholders to develop promotional materials illustrating contributions of persons with DD as members of Maine's workforce.	Year 1: Collaborate to develop promotional materials

and 500 members of the general public to increase their understanding of the employment contributions of individuals with developmental disabilities.	2. Redesign Council website to feature information about integrated employment, and highlight contributions of individuals with DD in integrated employment settings. 3. Conduct public awareness activities to promote expanded availability of integrated employment opportunities for persons with DD. 4. Provide information to the State Legislature and other policymakers about the unemployment rates for persons with DD, and the opportunities/benefits of providing opportunities for gainful employment in integrated settings. 5. Support Speaking Up For Us in community outreach activities & advocacy activities with policymakers.	Year 1: Feature integrated employment as part of 40th Anniversary Celebration. Year 1: Complete website redesign Annually: provide information re employment issues & opportunities in annual report to Legislature. Year 1: Develop strategic plan for Council use of public & social media in community outreach activities related to employment issues. Year 2: Implement strategic plan. Ongoing: provide support to Speaking Up for Us.
Participate in initiatives that result in at least 3,000 members of the public having opportunities to expand their understanding of the value of community inclusion and accessibility for persons with disabilities.	1. Redesign Council website, to include pages that offer stories & promote community inclusion & accessibility for persons with disabilities. 2. Develop & implement strategic plan to increase Council use of public media in activities to raise community awareness of issues affecting persons with DD and their families. 3. Collaborate with stakeholders to plan and coordinate a 40th anniversary celebration of Council activities and progress in achieving community inclusion & equal opportunities for persons with DD. 4. Develop Council capacity to utilize social media in support of activities and advocacy.	Year 1: Redesign Council website for launch as part of 40th Anniversary celebration. Year 1: Plan & conduct 40th anniversary celebration December 2011-March 2012 Year 1: Train Council members & staff in use of website, social & public media for communicating with public & policymakers.

	5. Support Speaking Up For Us in community outreach and education efforts.	Year 1: Develop strategic plan for use of media in Council activities. Year 2 & ongoing: Implement strategic plan. Ongoing: Provide support for Speaking Up For Us activities.
Engage in at least three initiatives that result in natural supports in inclusive community activities being available to at least 50 individuals with developmental disabilities, and the recognition of contributions of individuals with DD in valued roles in their communities.	1. Provide support for education & awareness activities conducted by the Maine Partnership for Values-Based Practice. 2. Promote the community benefit of inclusion & the provision of natural supports through the Council's public awareness activities, including use of annual reports & social media. 3. Highlight the community contributions of individuals with developmental disabilities, including SUFU membership, in educational materials provided to state & federal policymakers. 4. Participate in outreach efforts to share the results of a Council-funded pilot project to integrate individuals with developmental disabilities in faith-based activities.	Year 1: Collaborate with pilot project grantee to share information with other faith-based organizations. Year 1: Provide support for two events to promote Values-Based Practices. Ongoing: include information promote community inclusion & contributions of individuals with disabilities in reports to state & federal policymakers
Support community awareness activities that result in at least 15 individuals with developmental disabilities being recognized as valued community members through their participation in the	1. Support a pilot project offering training & support to individuals with DD in the use of cameras & photography as a means of personal expression. 2. Support opportunities for individuals with DD to share their art work through the provision of gallery space at the Council office, & promotion of art exhibits. 3. Support opportunities for individuals with DD to participate in integrated community recreation.	Year 1: Provide funding and support for photography project. Year 1: Arrange for public display of photographs & media coverage. Ongoing: provide gallery space at Council office.

arts and recreation.		Year 1: Include in website redesign a gallery page to feature artwork of persons with DD Spring, 2012 & continuing: promote art exhibits and feature artwork on Council website & in social media. Year 2-4: Provide support for new initiatives to offer integrated community recreation opportunities

Intermediaries/Collaborators Planned for this goal (if known):

[x] State Protection and Advocacy System

[x] University Center(s)

[x] State DD Agency

Community Service Providers

Family organizations

Self-advocacy organization, Speaking Up For Us

Section V: Evaluation Plan [Section 125(c)(3) & (7)]

PART A: Outline:

The variety of goals and activities being proposed in this plan require multiple methods and approaches to evaluation. Evaluation of goals and objectives will meet three important criteria: to determine whether Council activities have influenced or changed the service delivery environment, to measure how effective various activities have been, and to provide the Council input on how other activities should be modified. The use of a logic model will help structure the Council's approach, but the Council's focus on systems change requires a flexible logic model that can assess progress in reaching goals by measuring multiple outcomes. The features of the logic model include Defining the Objective, Inputs, Expected Outcomes, and Measurement Criteria. Measurement criteria will include process and progress milestones. For process evaluation, we will focus on efforts made to implement the goal (e.g. number of meetings attended, number of times Council representatives provide legislative testimony, etc.). For outcome evaluations we will focus on two key factors: quantifying numbers of individuals involved in activities related to implementing goals (e.g. number attending a training, number testifying at public hearings) as well as the impact of meeting our goals on individuals with developmental disabilities (e.g. number removed from waiting lists, number of policy recommendations adopted, etc.)

It will be important to measure progress at different points in time since activities related to meeting objectives may need to be changed or modified periodically. We also need to know if we have met an objective, so we can switch from a focus on change to sustaining the new environment. This will allow us to both identify successes in meeting objectives and measure effectiveness of methods being used to meet objectives still in progress. For quantitative data we will rely on primary and secondary data sources. For primary data collection, we will rely on systems set up within the council for tracking such items as number of participants in Council-sponsored trainings, workshops, or other sponsored events, our legislative tracking system to count bills introduced and number of times the Council provides testimony. In addition, we will track items such as number of meetings with collaborators, number and types of policies influenced, and number of requests for information received. We will also collect data using focus groups, key informant interviews, and group interviews to acquire qualitative data related to such things as consumer satisfaction with services, formative research related to service delivery needs, and input on Council priorities. We will use information provided by state agencies as secondary data sources to measure access outcomes and policy change impact on client services. Examples of secondary data that will be examined to measure progress related to the service delivery system will include reports and data related to the number of individuals receiving services (by type of service).

PART B: Methodology to determine needs being met and Council results being achieved:

We have divided the evaluation section into the 4 goals included in this plan and provided examples of how the methodology discussed in Part A will be applied to the goals. Below we provide examples of the approach we will take to evaluate the overall goal and individual objectives. Due to space limitations, we are providing examples for only 2 of the 4 objectives.

Goal 1: Improve access to quality comprehensive services and supports.

Several objectives in this goal related to improvement of services through both council-directed activities and supporting collaborators in improving services. As an example of the logic model approach, we have selected influencing policies to improve service delivery.

- Desired objective. Many of the Council's goals involve changing state policy related to services for persons with developmental disabilities. This may include adoption of new laws or regulations, changing existing rules and regulations, supporting positive laws or regulations that others may wish to change or repeal, or repeal of inappropriate or outmoded laws, policies, and rules.
- Example of Inputs: Legislative testimony, participation on policy committees, public input through hearings, issue papers and policy briefs, meetings with policymakers, collaborative efforts with partners.
- Example of Expected outcomes: New legislation adopted and signed, new policies issued by state, repeal of undesirable policies, agreement to study policies.
- Example of Measurements of Progress: Numbers of people impacted by the policy, number of process steps needed to accomplish goals, number of individuals impacted by policy changes, successful attempts to defend appropriate policies from change, etc.

Goal 3: Increase participation of self-advocates in policymaking.

- Desired Objective. The council works to help self-advocates participate in policymaking through both collaborative efforts with self-advocacy organizations and through training of self-advocates in how to become involved in policymaking. Through the Council's Leadership Institute, we train self advocates and family members regarding legislative and rulemaking processes, how to testify at hearings or other public meetings, and how to organize community efforts to improve services.
- Example of Inputs: Organize a series of trainings within the framework of the Leadership Institute, provide assistance with identifying issues of concern for self-advocates and creating policy briefs, support Speaking Up for US, provide direct assistance to families or individuals in need of assistance in changing policies by working with governmental agencies, school districts, or medical providers.

- Examples of Expected Outcomes: More self-advocates and family members enrolling in the Leadership Institute, more self-advocates testifying at public hearings, more SUFU involvement in policy change.
- Examples of Measurements: Number of Leadership Institute graduates, number of self-advocates testifying at hearings and public meetings.

PART C: Council's role in reviewing and commenting on progress of the Plan Goals:

As Maine is a minimum allotment state, the number and scope of potential projects are limited by available resources. This allows the full Council the opportunity to participate in significant ongoing review of the relevance and value of its activities, as well as its progress towards the goals of the State Plan. Council participation is assured through a range of activities.

Each Council project has a corresponding committee that serves in an advisory/oversight capacity. The committee roles vary depending upon the nature and scope of the project, and may change as experience dictates. The committees of the Council have been reorganized to assure more in-depth analysis of public policy activities, as well as a more strategic evaluation of quality measures and systemic problems, as well as more effective community outreach to influence public perceptions and collect information which will contribute to the Council's work. This reorganization presents an opportunity to specifically address appropriate evaluation activities for specific Council activities as a core responsibility of the Committees. For example, the statewide self advocacy organization initially involved significant Council involvement and staff time as well as financial support; at this stage of its existence, the Council provides oversight of its resources through contract management, evaluation of quarterly progress reports, and collaborative interaction in a variety of venues and on a wide range of mutual interests.

The Council incorporates project progress reports into each of its (quarterly) meetings. These serve to provide regular updates to all Council members regarding activities related to all goals and objectives. Individual Council members may be closely involved in specific projects and may provide updates with staff support as needed.

The Council identifies budgetary priorities annually, by identifying general resource allocations corresponding to activities associated with goals and objectives. On a quarterly basis, as needed, the Council reviews and approves changes to allocations in response to emerging trends and needs.

The Council reviews information and data that is submitted in the Comprehensive Review updates. This information about changes in various aspects of the service environment that informs the achievement and/or modification of State Plan goals and objectives.

The Council also reviews available consumer satisfaction data to provide input to increasing the breadth and depth of that input. Council members assisted with facilitation of public forums during the 5 Year Plan development process.

The Council reviews the state plan annually to determine progress towards goals and objectives and to determine necessary modifications to the Plan to respond to emerging issues.

The Executive Committee is available at short notice to respond to emergent concerns that may affect implementation of the State Plan of achievement of goals.

PART D: How the annual review identify trends and needs and for updating the Comprehensive Review and Analysis section:

The Council continuously gathers and disseminates qualitative and quantitative information available at a state and national level with the goal of providing relevant, timely and comprehensive information to stakeholders and participating effectively in policymaking activities.

At each Council meeting and through interim communications, state agency representatives to the Council provide or facilitate access to data regarding quality markers such as wait lists and unmet needs, to information regarding service delivery, and proposed changes to the system. DD Network Partners and the statewide self advocacy organization provide information regarding best practice, advocacy issues and self advocate concerns. Staff assists with reporting regarding legislative issues, when applicable, as well as with gathering and sharing information and data from national sources, both state specific as well as that from a contextual (regional and national) perspective. Committees may be further involved in gathering information regarding specific issues. This continuous loop of information gathering and sharing creates an environment in which emerging issues are identified early and carefully tracked.

The annual review of the state plan is completed through the Council committees and a meeting of the full Council to consider any recommended/necessary modifications. An overview of current and emerging systems issues and concerns is presented for Council consideration. These are included in the update of the Comprehensive Review and Analysis. Emerging needs and trends identified by the Council are further used to identify situations in which the State Plan may need to be modified.

The Council is committed to increasing its members and stakeholders understanding of and involvement in state and national policy issues affecting services and supports for person with developmental disabilities. To that end, parent and self advocate members attend the national disability policy conference and share information with the full Council, as well as with other stakeholders.

Section VI: Projected Council Budget [Section 124(c)(5)(B) and 125(c)(8)]

Goal	Subtitle B $	Other(s) $	Total $
1. Access to Quality Comprehensive Services and Supports	$154,614.00	$15,000.00	$169,614.00
2. Opportunities for Inclusion as Valued Members of Communities	$137,892.00	$10,000.00	$147,892.00
3. Self-Advocacy	$211,891.00	$50000.00	$261,891.00
4. Self-Determination	$72,845.00	$35000.00	$107,845.00
5. General Management	$23,930.00	$4000.00	$27,930.00
6. Functions of the DSA	$0.00	$2000.00	$2,000.00
7. TOTALS	$601,172.00	$116,000.00	$717,172.00

Section VII: Assurances [Section 124(c)(5)(A)-(N)]

Written and signed assurances must be submitted to the Administration on Developmental Disabilities, Administration for Children and Families, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C)(5)(A) - (N) in the Developmental Disabilities Assurance and Bill of Rights Act.

[x] Assurances submitted

Approving Officials for Assurances:

[x] For the Council (Chairperson)

[x] For DSA, when not Council

Section VIII: Public Input and Review [Section 124(d)(1)]

PART A: How the Council made the plan available for public review and comment and how the Council provided appropriate and sufficient notice in accessible formats of the opportunity for review and comment.

The Plan was made available for public review and comment for 45 days as required on the Council website and via the Council's email network. The Council and its partners promoted public review thru print and internet-based newsletters and social media. The Council also used an on-line survey to collect public input and compile comments received. The electronic version of the plan was accessible to visual modification and screen reading programs, and was shared with partners with accessible websites. Print copies were given to Speaking Up for Us for self-advocates who don't have access to the internet, and the Council made staff available to assist SUFU with outreach to obtain review and comment. One Council member presented the draft plan in person at his local town meeting. Comment was primarily received via an electronic survey, with the majority of comments received within the first 10 days of posting The Council received substantially more comment than it did for the previous 5 year Plan.

PART B: Revisions made to the Plan after taking into account and responding to significant comments.

The Council revised several objectives and added some activities in response to public61 comment. None of the changes made were felt to substantially alter the plans content or intent.

Obj 1.4: Removed the modifier "rural" referring to "health care provider". The Council agreed that this would not require changes to current activities and would increase responsiveness to emergent issues.

Obj 2.2: Merged 2 proposed objectives into one slightly broader one.

Obj 2.3: Changed target number to 100 in response to strong feedback that the initial target was too high.

Goal 4: "Visible, active" was added to modify "valued members" of the community. The Council felt that the additional modifier clarified the intent.

Obj 4.1: Eliminated verbiage specifying elimination of certain services in response to feedback that the statement could be perceived as inflammatory.

The scope of some of the activities was slightly broadened with the inclusion of potential stakeholders.

ALLOCATION OF EXPENDITURES BY SOURCE OF FUNDING

FFY04 - FFY11

	2004			2005			2006		
	Part B $	**Match $**	**Total**	**Part B $**	**Match $**	**Total**	**Part B $**	**Match $**	**Total**
State Councils on DD	$466,647	$55,796	$522,443	$379,833	$78,764	$458,597	$348,728	$49,721	$398,449
Designated State Agency	$0	$22,319	$22,319	$0	$22,931	$22,931	$0	$3,553	$3,553
Other(s) State Agency	$0	$0	$0	$0	$0	$0	$0	$0	$0
State Protection & Advocacy Agency	$0	$0	$0	$69,036	$5,081	$74,117	$80,963	$1,423	$82,386
University Centers for Excellence in Dev. Disabilities Studies	$0	$13,212	$13,212	$0	$25,609	$25,609	$0	$27,482	$27,482
Non-Profit Organizations	$50,000	$0	$50,000	$0	$8,329	$8,329	$0	$28,041	$28,041
Other	$0	$0	$0	$0	$18,422	$18,422	$0	$0	$0
Total	**$516,647**	**$91,327**	**$607,974**	**$448,869**	**$159,136**	**$608,005**	**$429,691**	**$110,220**	**$539,911**

ALLOCATION OF EXPENDITURES BY SOURCE OF FUNDING

FFY04 - FFY11

	2007			2008			2009		
	Part B $	Match $	Total	Part B $	Match $	Total	Part B $	Match $	Total
State Councils on DD	$322,724	$71,178	$393,902	$324,629	$85,175	$409,804	$362,633	$69,836	$432,469
Designated State Agency	$0	$3,844	$3,844	$0	$3,563	$3,563	$0	$1,898	$1,898
Other(s) State Agency	$0	$10,655	$10,655	$0	$94,324	$94,324	$0	$108,860	$108,860
State Protection & Advocacy Agency	$75,000	$7,787	$82,787	$75,000	$17,115	$92,115	$0	$6,099	$6,099
University Centers for Excellence in Dev. Disabilities Studies	$0	$30,486	$30,486	$0	$36,457	$36,457	$0	$34,169	$34,169
Non-Profit Organizations	$0	$9,304	$9,304	$0	$37,206	$37,206	$93,807	$51,076	$144,883
Other	$0	$45,403	$45,403	$13,031	$22,672	$35,703	$7,810	$32,563	$40,373
Total	**$397,724**	**$178,657**	**$576,381**	**$412,660**	**$296,512**	**$709,172**	**$464,250**	**$304,501**	**$768,751**

ALLOCATION OF EXPENDITURES BY SOURCE OF FUNDING

FFY04 - FFY11

	2010			2011		
	Part B $	Match $	Total	Part B $	Match $	Total
State Councils on DD	$339,623	$48,000	$387,623	$343,453	$91,595	$435,048
Designated State Agency	$0	$1,898	$1,898	$0	$1,898	$1,898
Other(s) State Agency	$0	$125,154	$125,154	$0	$21,964	$21,964
State Protection & Advocacy Agency	$700	$4,838	$5,538	$0	$4,121	$4,121
University Centers for Excellence in Dev. Disabilities Studies	$0	$35,796	$35,796	$0	$31,004	$31,004
Non-Profit Organizations	$115,230	$58,713	$173,943	$115,855	$31,992	$147,847
Other	$3,950	$12,060	$16,010	$7,246	$270,778	$278,024
Total	**$459,503**	**$286,459**	**$745,962**	**$466,554**	**$453,352**	**$919,906**

ALLOCATION OF EXPENDITURES BY EMPHASIS AREA and ADMINISTRATIVE COSTS FFY04-FFY11

	2004				2005				2006			
	Part B $	Other	Total	%	Part B $	Other	Total	%	Part B $	Other	Total	%
Employment	$5,304	$0	$5,304	0.9%	$11,531	$1,044	$12,575	2.1%	$22,637	$1,555	$24,192	4.5%
Housing	$5,916	$0	$5,916	1.0%	$7,100	$575	$7,675	1.3%	$1,102	$278	$1,380	0.3%
Health	$107,508	$0	$107,508	18.4%	$81,393	$3,083	$84,476	14.4%	$22,761	$3,826	$26,587	4.9%
Education & Early Intervention	$39,546	$0	$39,546	6.8%	$30,823	$2,834	$33,657	5.8%	$15,229	$4,481	$19,710	3.6%
Child Care	$3,612	$0	$3,612	0.6%	$3,267	$353	$3,620	0.6%	$2,297	$207	$2,504	0.9%
Recreation	$3,198	$0	$3,198	0.5%	$5,266	$535	$5,801	1.0%	$1,039	$51	$1,090	0.5%
Transportation	$1,250	$0	$1,250	0.2%	$5,056	$1,601	$6,657	1.1%	$1,663	$308	$1,971	0.4%
Quality Assurance	$197,749	$55,796	$253,545	43.3%	$176,581	$92,517	$269,098	46.0%	$249,974	$60,174	$310,148	57.4%
Formal & Informal Community Support	$61,365	$0	$61,365	10.5%	$59,629	$5,981	$65,610	11.2%	$34,251	$5,076	$39,327	7.3%
General Mgmt	$91,199	$13,212	$104,411	17.8%	$68,223	$27,682	$95,905	16.4%	$78,738	$30,711	$109,449	20.3%
Functions of the DSA	$0	$22,319	$22,319		$0	$22,931	$22,931		$0	$3,553	$3,553	
TOTALS	**$516,647**	**$91,327**	**$607,974**		**$448,869**	**$159,136**	**$608,005**		**$429,691**	**$110,220**	**$539,911**	
Federal Funds for General Mgmt (% of total Federal Funds expended)	17.7%				15.2%				18.3%			

ALLOCATION OF EXPENDITURES BY EMPHASIS AREA and ADMINISTRATIVE COSTS FFY04-FFY11

	2007				2008				2009			
	Part B $	Other	Total	%	Part B $	Other	Total	%	Part B $	Other	Total	%
Employment	$10,241	$410	$10,651	1.9%	$12,736	$27,021	$39,757	5.6%	$10,270	$4,243	$14,513	1.9%
Housing	$556	$0	$556	0.1%	$1,523	$0	$1,523	0.2%	$3,700	$2,638	$6,338	0.8%
Health	$20,353	$3,147	$23,500	4.1%	$24,921	$1,211	$26,132	3.7%	$63,177	$45,842	$109,019	14.2%
Education & Early Intervention	$31,683	$19,733	$51,416	9.0%	$58,497	$32,406	$90,903	12.9%	$78,028	$58,773	$136,801	17.8%
Child Care	$312	$0	$312	0.1%	$0	$0	$0	0.0%	$0	$0	$0	0.0%
Recreation	$170	$0	$170	0.0%	$0	$0	$0	0.0%	$0	$0	$0	0.0%
Transportation	$2,388	$0	$2,388	0.4%	$0	$0	$0	0.0%	$0	$0	$0	0.0%
Quality Assurance	$245,002	$102,666	$347,668	60.7%	$224,254	$158,167	$382,421	54.2%	$232,066	$152,951	$385,017	50.2%
Formal & Informal Community Support	$36,293	$18,163	$54,456	9.5%	$59,482	$47,421	$106,903	15.2%	$33,214	$20,443	$53,657	7.0%
General Mgmt	$50,726	$30,694	$81,420	14.2%	$31,247	$26,723	$57,970	8.2%	$43,795	$17,713	$61,508	8.0%
Functions of the DSA	$0	$3,844	$3,844		$0	$3,563	$3,563		$0	$1,898	$1,898	
TOTALS	**$397,724**	**$178,657**	**$576,381**		**$412,660**	**$296,512**	**$709,172**		**$464,250**	**$304,501**	**$768,751**	

Federal Funds for General Mgmt (% of total Federal Funds expended)	12.8%	7.6%	9.4%

ALLOCATION OF EXPENDITURES BY EMPHASIS AREA and ADMINISTRATIVE COSTS FFY04-FFY11

	2010				2011			
	Part B $	Other	Total	%	Part B $	Other	Total	%
Employment	$8,629	$7,620	$16,249	2.8%	$7,321	$665	$7,986	0.9%
Housing	$10,028	$1,880	$11,908	2.1%	$3,520	$125	$3,645	0.4%
Health	$100,426	$32,922	$133,348	23.3%	$90,026	$180,405	$270,431	29.5%
Education & Early Intervention	$33,743	$22,591	$56,334	9.8%	$39,076	$101,799	$140,875	15.3%
Child Care	$0	$0	$0	0.0%	$0	$0	$0	0.0%
Recreation	$0	$0	$0	0.0%	$0	$0	$0	0.0%
Transportation	$0	$0	$0	0.0%	$1,453	$51	$1,504	0.2%
Quality Assurance	$247,237	$192,356	$439,593	76.8%	$278,289	$134,066	$412,355	44.9%
Formal & Informal Community Support	$44,739	$5,927	$50,666	8.8%	$35,251	$7,603	$42,854	4.7%
General Mgmt	$14,701	$21,265	$35,966	6.3%	$11,618	$26,740	$38,358	4.2%
Functions of the DSA	$0	$1,898	$1,898		$0	$1,898	$1,898	
TOTALS	**$459,503**	**$286,459**	**$745,962**		**$466,554**	**$453,352**	**$919,906**	

Federal Funds for General Mgmt (% of total Federal Funds expended)	3.2%				2.5%			

Maine Developmental Disabilities Council

Program Performance Report

For Federal Fiscal Year 2011

Prepared on Tuesday, January 10, 2012

Executive Director: Julia Bell

Maine Developmental Disabilities Council
139 State House Station

Augusta, ME 04333

Section 1: Identification

State or Territory: Maine Developmental Disabilities Council
Reporting Period: October 1, 2010 - September 30, 2011

Name of Person to Contact Regarding PPR Information		**State Authority**
Contact Last Name	Bell	State Authority Establishing Council:
Contact First Name	Julia	State Statute
Phone	(207) 287-4215	Did the state authority change in this fiscal year?
Email	julia.j.bell@maine.gov	Yes | No ✓
Designated State Agency		
Did your DSA change?	Yes | No ✓	
If yes, Name?		
Is the new DSA a service provider?	Yes | No | N/A ✓	

Section 2: Comprehensive Review

Comprehensive Review and Analysis Update

The economic situation in Maine continues to be of great concern. While unemployment rates have stabilized, they have been sustained at a high level for a longer time than has been seen in at least 35 years. Food, fuel and general assistance, as well as charities, continue to report very high demand. As the availability of federal stimulus dollars has come to an end services have been restricted or eliminated in a wide array of program areas important to persons with developmental disabilities. The past several biennial budgets have experienced significant annual shortfalls with intervening reductions focused on educations and health and human services. The November 2010 election resulted in a complete change of political control in the state. The current gubernatorial administration has focused on cutting state income taxes even in the face of serious shortfalls in critical services. There is grave concern that additional human service funding is at risk as the focus of the next round of budget discussions will be reducing Medicaid expenditures. Access to Developmental Services (for those who are eligible) first became significantly limited, even to those in serious jeopardy, 3 years ago. The waitlist for the Home and Community-based Services Waiver for adults with MR/Autism has increased 900% since 08, with an increase in FY11 alone of 25% (to 500 persons, 200 of whom are in adult protective� status. Access to the Community Supports Waiver, which provides a narrower array of services (esp. day programming and employment supports), was first limited 2 years ago. Persons have been added to this waiver on a first come first serve basis pending available resources; nevertheless by the end of FY11 a waitlist of over 300 persons has developed (an increase of 60% in FY11 alone). The Crisis System is at capacity, with some services being funded with 100% state general fund dollars because of the closure of the waiver. There is also significant concern that the current situation will further restrict and/or eliminate activities that promote community integration and independence, focusing instead only on health and safety�. There is still no systemic approach to meeting the needs of adults with developmental disabilities who do not meet diagnostic criteria for intellectual disability or autism. The Community Consent Decree was settled in late FY10. The Council, with other advocacy groups, is monitoring due to concern that the closure result in a decrease in commitment to developmental services. A very few persons with developmental disabilities (approximately 160) receive services in ICFs/MR. These are all small, privately operated facilities and tend to support medically fragile pwdd; a significant portion are certified as nursing facilities. This type of service is not expected to grow. Services to children with developmental disabilities have also sustained cuts this year. Case management has been limited and significant changes to in home supports and early childhood services have been enacted. The Council has heard anecdotes of children having increased difficulty accessing services. Overall unemployment has been sustained at rates not seen in decades; people with disabilities continue to be the most significantly under-employed. The focus of state efforts for work incentives (in terms of fiscal effort) has been to address employment disparities for women, although the needs of women w/ disabilities have not been specifically addressed. The work incentive system is changing in response to the priorities of the new administration; the Council is monitoring and advocating for the needs of workers with developmental disabilities. The VR system continues to operate with no wait list. The state continues with its MIG to address employment for persons with disabilities, focusing on raising awareness and providing outreach and support to employers, especially large employers, and providing training to employment specialists. Housing prices and sales have continued to be depressed, with high demand on the affordable housing market. Many Mainers with developmental disabilities live in housing owned by agencies that are adversely affected by the decreased availability of credit and anxiety of lenders about their ability to meet obligations in light of the state budget.

Wait List	Previous Year	Current Year
Home & Community Based Waiver - Adults with I	396	499
Physical Disabilities HCBS Waiver - consumer	112	73
Vocational Rehabilitation Services	0	0
Community Supports Waiver - Adults with ID/Au	205	321
Community Employment - Adults with ID/Autism	41	54
Targeted Case Management - Children	52	14
In-Home Supports - Children with DD	51	59

Section 3: Areas of Emphasis and Performance Targets

Child Care

Children & families benefit from a range of inclusive, flexible childcare options.
The Council has continued to participate in the work of the Early Childhood Task Force which focuses on systems change activities to address the lack of resources and lack of training for child care providers.

Outcomes in Child Care

CH01 - Children in inclusive child care settings through Council efforts	0
CH02 - Dollars leveraged for child care programs	$0.00
CH03 - Child care programs/policies created/improved	0
CH04 - People facilitated inclusive childcare	0
CH05 - People trained in childcare	0
CH08 - Other	0
CH08 - Other	0
CH08 - Other	0

Section 3 Projects and/or Activities

Informing Public Policymakers re Child Care I

Implementer:	✓ in house by contract/grant	Goal Area	Child Care
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2005	Ending Date:	9/30/2011
Part B Funds:	$0.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a)

b)

c)

d)

e)

f)

g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Thru Disability Advocacy Coalition work, participation in State advisory councils, and through Leadership Institute, promote and participate in advocacy for fully inclusive child care programs.

Section 3: Areas of Emphasis and Performance Targets

Cross Cutting

The Council has drawn attention to issues of importance to persons with disabilities and their families through the press, public appearances, and through its website and a cascade of listservs. The Council also provides regular updates on current public policy issues, esp pending legislation at the state and national level, through its website and newsletters/websites of other organizations. Through participation in a variety of initiatives involving a broad spectrum of organizations and individuals, the Council has been able to educate others about mutual concerns and encourage increased collaboration.

Outcomes in Cross Cutting

CR01 - Public policymakers educated about issues related to Council Initiatives	210
CR02 - Number of distinct products distributed to policymakers about issues related to Council Initiatives	15
CR03 - Members of the general public estimated to have been reached by Council public education, awareness and media initiatives	294,900

Section 3: Areas of Emphasis and Performance Targets

Formal and Informal Community Supports

Individuals have access to other services available or offered in a community, including formal and informal community supports that affect their quality of life.

Due to continued state budget shortfalls in FYs 11 /12 and a projected shortfall into the next biennium, efforts in the area of community supports have focused on monitoring the potential and real impact of budget cuts and education regarding the potential harm of curtailment of services. Due to personnel changes resulting from a new executive administration (removal of political appointees & retirements in response to downsizing government initiatives), the Council has redoubled legislative education efforts (needed to protect community supports) and initiated departmental education (due to lack of specific administrative expertise in developmental disabilities). The Council continues to work with its sister organizations under the DD Act and with others to assure that quality of life issues, in addition to health and safety issues, are addressed. The Council was instrumental in legislative advocacy efforts during the budget planning process that ameliorated significant proposed cuts to adult developmental services.

The Council continues to work toward the goal of assuring that persons with disabilities are included in emergency preparedness planning and response in Maine. The Council worked closely with the Legislative Task Force on Homeland Security and the Joint Legislative Committee on Criminal Justice and Public Safety, and continues to work with the Maine Emergency Management Agency (MEMA), to address a wide range of issues critical to persons with disabilities in planning for potential emergencies.

The ASD Implementation Grant has achieved recognition in its efforts to develop improvements to the current service system and to identify priorities for continuing change. This project, as well as work on a legislative report regarding the state�s restrictive criteria for developmental services, has raised awareness that there are significant gaps in the availability of comprehensive community services for all persons with developmental disabilities. The Council also provided funding and staff involvement in arranging for and hosting a social role valorization workshop, the first of its kind available in Maine in several years. This first workshop drew 112 participants.

Outcomes in Formal and Informal Community Supports

CS01 - Individuals benefit from formal/informal community supports as a result of Council efforts	58
CS02 - Dollars leveraged for formal/informal community supports	$5,600.00
CS03 - Formal/informal community supports programs/policies created/improved	2
CS04 - People facilitated formal/informal community supports	5
CS05 - People trained in formal/informal community supports	508
CS08 - Buildings/public accommodations became accessible	0
CS09 - Other	0
CS09 - Other	0
CS09 - Other	0

Section 3 Projects and/or Activities

Access to Community Supports

Implementer:	✓ in house by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2003	Ending Date:	9/30/2016
Part B Funds:	$8,892.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Association of Community Service Providers
b) Autism Society of Maine
c) Maine Equal Justice Partners
d) Alpha One
e) State Independent Living Council
f) Office of Advocacy, Maine Department of Health and Human Services
g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Evaluate federal & state policies, quality review reports, and other data and participate in review of current systems of care, and evolution of systems to achieve full community inclusion for PWDD.

Section 3 Projects and/or Activities

ASD State Implementation Grant - Community Su

Implementer:	✓ in house by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	8/31/2013
Part B Funds:	$0.00	Other Funds:	$5,069.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Education
b) Maine Department of Health and Human Services
c) Maine Department of Labor
d) Autism Society of Maine
e) parents
f) self-advocates
g) community service providers

Primary Activity Type

Interagency Coordination & Collaboration

Project Activity Description

Coordinate an initiative addressing the need for increased capacity and effectiveness in services/supports for individuals with autism and other pervasive developmental disorders across the life span.

Section 3 Projects and/or Activities

Community Inclusion for Adults

Implementer:	in house ✓ by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):	independent contractors		
Beginning Date:	9/1/2010	Ending Date:	9/30/2012
Part B Funds:	$8,814.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Maine State Department of Health and Human Services
b) Service provider representatives
c)
d)
e)
f)
g)

Primary Activity Type

Training

Project Activity Description

Contract will fund training focused on integrating persons with DD into communities - Social Role Valorization. Contract development completed in FY10.

Section 3 Projects and/or Activities

Emergency Preparedness

Implementer:	✓ in house by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):			
Beginning Date:	6/1/2005	Ending Date:	9/30/2013
Part B Funds:	$1,889.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Health and Human Services
b) Maine Emergency Management Agency
c) Speaking Up For Us
d) Maine Primary Care Association
e) Autism Society of Maine
f) State Independent Living Council
g) Maine Regional Resource Centers, U.S. Centers for Disease Control

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

Assure that emergency preparedness planning efforts in Maine involve people with disabilities and assure their needs and rights will be appropriately addressed.

Section 3 Projects and/or Activities

Informing Public Policy Makers re Community S

Implementer:	✓ in house by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2006	Ending Date:	9/30/2016
Part B Funds:	$14,755.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a)

b)

c)

d)

e)

f)

g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Advocacy activities and training regarding community supports issues are included under the Maine Disability Advocacy Coalition & Disability Leadership Institute

Section 3 Projects and/or Activities

Multicultural Awareness

Implementer:	in house ✓ by contract/grant	Goal Area	Formal and Informal Community Supports
Grantee/Contractor Name (if appropriate):	Maine Parent Federation		
Beginning Date:	1/1/2010	Ending Date:	9/30/2010
Part B Funds:	$0.00	Other Funds:	$0.00
Intermediaries/Collaborators:	State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a)

b)

c)

d)

e)

f)

g)

Primary Activity Type

Outreach

Project Activity Description

Contract supports outreach efforts in African refugee community regarding availability of services for children & youth with disabilities.

Section 3: Areas of Emphasis and Performance Targets

Education and Early Intervention

Students reach their educational potential and infants and young children reach their developmental potential.

The Council facilitated and staffed the Maine Education Advocacy Alliance, a collaboration of organizations which focus on families and education issues (the Council, Maine Parent Federation, Disability Rights Center, Maine Transition Network, Autism Society of Maine, and Learning Disabilities Association). Many parents have joined local advocacy groups and internet listservs through Alliance efforts, enabling more rapid and effective opportunities to provide information to families, educate them about pending changes in statute & rules, and promote their involvement in policy-making activities. The Council is represented on the Maine Department of Education�s special education advisory board, which provides input to that agency on issues related to compliance with federal statutes and rules regarding special education services. The Council has been active in making legislative recommendations for increasing the effectiveness of early childhood education and has participated in a work group addressing behavioral and restraint regulations in schools, w/ proposed rules expected in FY12. Through the ASD Implementation Grant, the Council has facilitated work groups which focused on early identification, early intervention and transition services. Significant changes in the structure and funding of early childhood services have put children previously eligible for early intervention services at risk; the Council expects to be engages in efforts to maintain the service system. The Council also advocated successfully for and participated in the work group responsible for rewriting sections of Maine's special education rules related to eligibility and services. Council projects have resulted in a significant increase in early screening and efforts to refer young children for early diagnostic and appropriate intervention services. A direct connection between the Council 's work and earlier access to services cannot be documented through available data at this time, but reports from physicians indicate they are referring children earlier and to both Child Development Services and diagnostic specialists.

Outcomes in Education and Early Intervention

ED01 - Students have the education and support they need to reach their educational goals through Council efforts	0
ED02 - Infants and young children have the services/supports needed to reach developmental goals through Council efforts	0
ED03 - Students transitioned from school to community and jobs	0
ED04 - Children transitioned from early intervention and pre-school to inclusive schools/classrooms	0
ED05 - People on waiting list(s) received services	0
ED06 - Dollars leveraged for education	$94,078.00
ED07 - Education programs/policies created/improved	6
ED08 - Post-secondary institutions improved inclusive education	0
ED09 - Schools improved IEP practices	0
ED10 - People facilitated inclusive education	4
ED11 - People trained in inclusive education	475
ED13 - Parents or guardians trained regarding their child's education rights	3
ED14 - Other	0
ED14 - Other	0
ED14 - Other	0

Section 3 Projects and/or Activities

ASD State Implementation Grant

Implementer:	✓ in house by contract/grant	Goal Area	Education and Early Intervention
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	8/31/2013
Part B Funds:	$0.00	Other Funds:	$81,410.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Autism Society of Maine
b) Maine Department of Health & Human Services
c) Maine Department of Education
d) Child Development Services
e) Maine Medical Partners
f) Eastern Maine Medical Center
g) Husson Pediatrics

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

This grant funded by HRSA continues the work begun by the Council under the PDD Systems Change Initiative, focusing on early intervention and transition services.

Section 3 Projects and/or Activities

Informing Public Policymakers re Education Is

Implementer:	✓ in house by contract/grant	Goal Area	Education and Early Intervention
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2006	Ending Date:	9/30/2011
Part B Funds:	$31,456.00	Other Funds:	$12,158.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators
a) Maine Parent Federation
b) Autism Society of Maine
c)
d)
e)
f)
g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Council is represented on the Maine Dept. of Education Advisory Council, and provides information to policymakers on pending legislation and rules affecting education of children with disabilities.

Section 3 Projects and/or Activities

Maine Education Advocacy Alliance

Implementer:	✓ in house by contract/grant	Goal Area	Education and Early Intervention
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2006	Ending Date:	9/30/2011
Part B Funds:	$6,595.00	Other Funds:	$455.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators
a) Maine Parent Federation
b) Learning Disabilities Association of Maine
c) Autism Society of Maine
d)
e)
f)
g)

Primary Activity Type

Informing Policymakers

Project Activity Description

DD Council organized & convenes this alliance of organizations to focus on collaborative advocacy & increased involvement of parents & youth in development & monitoring of public education policies.

Section 3 Projects and/or Activities

Promotion of Assistive Technology for Childre

Implementer:	✓ in house ✓ by contract/grant	Goal Area	Education and Early Intervention
Grantee/Contractor Name (if appropriate):	Technology Exploration Center		
Beginning Date:	4/1/2008	Ending Date:	3/31/2009
Part B Funds:	$9,633.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Parent Federation

b) Maine Department of Education

c) MaineCITE

d)

e)

f)

g)

Primary Activity Type

Demonstration of New Approaches to Services and Supports

Project Activity Description

This was a one-year project, begun in April 2008, to promote increased access to assistive technology for children with disabilities in educational settings, and universal design.

Section 3: Areas of Emphasis and Performance Targets

Employment

People get and keep employment consistent with their interests, abilities and needs.
The Council continues to participate as a member of the Commission on Disability and Employment. CDE activities include oversight of the MIG employment options grant (including training and outreach) & steering committee to the Disability Program Navigator project. There was a significant decrease in the department�s reported unmet need for community employment. This appears to be related to changes in data collection rather than an increase in employment of pwdd. The VR waiting list was also eliminated this year. The Council is working with the Dept of Labor to assure that pwdd are not found ineligible for services. The Council co-sponsored an �Employment First & for All� conference attended by nearly 100 individuals, representing a variety of geographical regions and sections of the service system. The conference focused on the importance of clear policies and practices related to employment first and integrated employment. Through its support for the statewide self-advocacy organization, Speaking Up For Us, the Council has also provided peer training on a variety of other issues key to successful community involvement, including in employment, and supported SUFU�s advocacy for �real pay for real work.� The Council provides exhibit space for VSA Arts shows as well as information about the artists w/ disabilities and assistance to purchasers of works for sale.

Outcomes in Employment

EM01 - Adults have jobs of their choice through Council efforts	29
EM02 - Dollars leveraged for employment	$0.00
EM03 - Employers provided vocational supports to students on the job	0
EM04 - Businesses/employers employed adults	0
EM05 - Employment programs/policies created/improved	1
EM06 - People facilitated employment	0
EM07 - People trained in employment	13
EM10 - Other	0
EM10 - Other	0
EM10 - Other	0

Section 3 Projects and/or Activities

Commission on Disabilities and Employment

Implementer:	✓ in house by contract/grant	Goal Area	Employment
Grantee/Contractor Name (if appropriate):			
Beginning Date:	2/1/2005	Ending Date:	9/30/2011
Part B Funds:	$2,245.00	Other Funds:	$100.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Labor
b) Muskie School of Public Policy, University of Southern Maine
c) APSE (previously Association for Persons in Supported Employment), Maine Chapter
d) Maine Transition Network
e) Individuals - self-advocates & parents
f) Department of Vocational Services, Maine Medical Center
g) Maine Department of Health and Human Services

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

Council collaborates with Commission members to disparities in employment opportunities for persons w/ disabilities. Activities focus on systemic change in public & private sector.

Section 3 Projects and/or Activities

Exhibit Gallery for Artists

Implementer:	✓ in house by contract/grant	Goal Area	Employment
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2003	Ending Date:	9/30/2016
Part B Funds:	$8,346.00	Other Funds:	$4,125.00
Intermediaries/Collaborators:	State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) VSA Arts of Maine

b)

c)

d)

e)

f)

g)

Primary Activity Type

Interagency Coordination & Collaboration

Project Activity Description

Maintain & advertise permanent gallery space & other exhibit areas in DD Council/UCEDD joint office space for VSA Arts of Maine shows of works produced & for sale by Maine artists with disabilities.

Section 3 Projects and/or Activities

Informing Public Policymakers re Employment I

Implementer:	✓ in house by contract/grant	Goal Area	Employment
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2005	Ending Date:	9/30/2011
Part B Funds:	$3,093.00	Other Funds:	$406.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Commission on Disability and Employment

b) SUFU

c)

d)

e)

f)

g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Advocacy activities and training regarding employment issues is included under the Maine Disability Advocacy Coalition & Disability Leadership Institute

Section 3 Projects and/or Activities

It\'s Your Life

Implementer:	in house ✓ by contract/grant	Goal Area	Employment
Grantee/Contractor Name (if appropriate):	Muskie School of Public Service, University o		
Beginning Date:	3/1/2008	Ending Date:	6/30/2009
Part B Funds:	$0.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Speaking Up For Us

b) Goodwill Industries Portland

c) Muskie School of Public Service, University of Southern Maine

d) Department of Health and Human Services, Office of Adults with Cognitive and Physical Disabilities

e)

f)

g)

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

Pilot program to assist in the transition from sheltered workshops utilizing a train-the-trainer model that partners employed persons with cognitive disabilities with those seeking employment.

Section 3 Projects and/or Activities

PDD Systems Change Initiative - Employment

Implementer:	✓ in house by contract/grant	Goal Area	Employment
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	8/31/2013
Part B Funds:	$0.00	Other Funds:	$0.00
Intermediaries/Collaborators:	State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine State Department of Labor
b) Maine State Department of Education
c) Maine State Department of Health & Human Services
d) Autism Society of Maine
e) Maine Parent Federation
f) Parents
g) Self-Advocates

Primary Activity Type

Interagency Coordination & Collaboration

Project Activity Description

Activities and resources included under other sections related to the ASD Systems Change Initiative.

Section 3: Areas of Emphasis and Performance Targets

Health

People are healthy and benefit from the full range of needed health services.
The Council continues to participate in health related education and advocacy efforts on a variety of topics. The Council is actively involved in the MaineCare Advisory Committee that monitors proposed changes to and effectiveness of Medicaid policy and is involved in advocacy specific to maintaining eligibility and a high level of service for children served through the Katie Beckett option. The Council participates in efforts to promote the inclusion of persons with disabilities in formal emergency preparedness planning and in educating health professionals about the needs and rights of persons with developmental disabilities in emergency situations. The Council has provided education regarding health care and health policy to participants in Advocacy Day, Disability Leadership Institute and through the statewide self advocacy organization, SUFU, including specific support regarding access to influenza vaccine. The Council shared info thru the Maine Disability Advocacy Coalition, which it staffs, about pending legislative proposals that would negatively affect health services for persons with disabilities to encourage & promote more involvement in advocacy by persons with disabilities and family members. A collaborative project to improve mental health services for people with developmental disabilities was initiated in Jan09 and originally planned to last 2 years. It has been extended an additional year because of positive response and will continue into FY12. With the assistance of a national expert, a statewide task force met three times and three sessions of introductory training were provided to approximately 150 persons statewide. Two sessions were held in very underserved rural areas. Through the efforts of the ASD Implementation grant, Maine has achieved nearly universal screening for autism, new screening tools were developed, training in their use was provided to primary care providers and training in diagnosis has begun. The Council initiated a collaborative project with Maine Primary Care Assn to address accessibility at federally qualified health centers. The Council successfully advocated requiring private insurance coverage for early intervention services for all young children up to age 3 who have development delays/disabilities and early intervention services for children from infancy up to age 6, who are on the autism spectrum disorder.

Outcomes in Health

HE01 - People have needed health services through Council efforts	1,040
HE02 - Dollars leveraged for health services	$160,400.00
HE03 - Health care programs/policies created/improved	23
HE04 - People improved health services	14
HE05 - People trained in health services	472
HE08 - Other	0
HE08 - Other	0
HE08 - Other	0

Section 3 Projects and/or Activities

ASD State Implementation Grant - Health Care

Implementer:	✓ in house by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	8/31/2013
Part B Funds:	$0.00	Other Funds:	$151,215.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Autism Society of Maine
b) Maine Department of Education
c) Maine Department of Health & Human Services
d) Maine Medical Partners
e) Maine Chapter, American Academy of Pediatrics
f) Two primary care medical practice offices in Portland and Bangor, Maine
g) Eastern Maine Medical Center

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

PDD Initiative continues focus on expanding early ID & early intervention services, enhanced medical home for children with ASDs. Second year of HRSA grant started September 1, 2011.

Section 3 Projects and/or Activities

Emergency Preparedness Collaboration with Pub

Implementer:	✓ in house by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):			
Beginning Date:	6/1/2005	Ending Date:	9/30/2011
Part B Funds:	$0.00	Other Funds:	$0.00

Intermediaries/Collaborators: State Protection and Advocacy System
University Center(s) of Excellence

Other Collaborators

a) Maine Emergency Management Agency
b) Maine Public Health Association
c) Maine Primary Care Association
d) Maine Center for Disease Control
e) Regional Resource Centers, U.S. Centers for Disease Control
f) State Independent Living Council
g) Speaking Up For Us

Primary Activity Type

Informing Policymakers

Project Activity Description

Work with other stakeholders and policymakers to assure PWD included in planning and have access to appropriate supports and services in emergency situations. \' see activity under Community Supports

Section 3 Projects and/or Activities

Informing Public Policymakers re Health Issue

Implementer:	✓ in house by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2006	Ending Date:	9/30/2016
Part B Funds:	$14,380.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) identified under Quality Assurance
b)
c)
d)
e)
f)
g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Address thru Disability Advocacy Coalition & Disability Leadership Institute. Council involved in working w/ legislators and state agency reps. to address Mcaid coverage for children w/ disabilites.

Section 3 Projects and/or Activities

PDD Physician Training

Implementer:	in house ✓ by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):	Maine Medical Center - Pediatric Specialty Ca		
Beginning Date:	1/1/2009	Ending Date:	9/30/2011
Part B Funds:	$11,340.00	Other Funds:	$0.00
Intermediaries/Collaborators:	State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Maine Medical Center - Developmental Pediatrics

b) Maine State Department of Health and Human Services

c)

d)

e)

f)

g)

Primary Activity Type

Demonstration of New Approaches to Services and Supports

Project Activity Description

Pilot project developed by developmental pediatricians to train primary care physicians to provide medical care for children with pervasive developmental disorders.

Section 3 Projects and/or Activities

Promoting access to quality medical care serv

Implementer:	✓ in house ✓ by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):	Maine Primary Care Association		
Beginning Date:	9/1/2006	Ending Date:	9/30/2014
Part B Funds:	$9,582.00	Other Funds:	$2,402.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Health and Human Services - MR/Autism Services
b) Maine Center for Disease Control
c) Maine Health Access Foundation
d) Alpha One
e) Maine Primary Care Association
f)
g)

Primary Activity Type

Training

Project Activity Description

Work with others to identify/eliminate physical barriers & lack of adequate training for medical care providers; & inclusion in public health initiatives for persons w/ disabilities.

Section 3 Projects and/or Activities

Promoting quality mental health services for

Implementer:	✓ in house ✓ by contract/grant	Goal Area	Health
Grantee/Contractor Name (if appropriate):	Robert Fletcher, DSW National Association for		
Beginning Date:	6/1/2006	Ending Date:	9/30/2012
Part B Funds:	$52,423.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Health and Human Services, Office of Adults with Cognitive and Physical Disabilities
b) Maine Department of Health and Human Services, Office of Adult Mental Health Services
c) Private mental health service providers
d) Community services providers for adults with DD
e) parents
f) self-advocates
g)

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

Three-year project to improve mental health care services for Mainers with developmental disabiities.

Section 3: Areas of Emphasis and Performance Targets

Housing

Adults choose where and with whom they live.
The Council has continued to work with the Maine Coalition for Housing and Quality Services to address advocacy efforts needed to protect the HOME fund (state housing authority set-aside for supportive housing options for persons w/ disabilities). In response to advocacy efforts, the Legislature passed a $30 million bond for affordable housing w/ 10% set aside for persons w/ disabilities. It is likely that further advocacy efforts will be needed in this area due to projected budgetary shortfalls. Housing prices and sales have continued to be depressed, with high demand on the affordable housing market. Many Mainers with developmental disabilities live in housing owned by agencies that are adversely affected by the decreased availability of credit & anxiety of lenders about their ability to meet obligations in light of the state budget. The Council has worked with a nationally recognized expert in affordable, integrated housing for people with disabilities to develop a proposal for follow up activities, which was accepted in concept by the Council w/ work on the initiative to begin in FY12. The Council's contract with Speaking Up For Us provides funding for trainings for self advocates regarding their rights and housing options, resulting in several self-advocates advocating successfully to move to other residential living situations with more independence.

Outcomes in Housing

HO01 - Individuals have homes of their choice through Council efforts	6
HO02 - People moved from congregate settings to homes in the community	0
HO03 - Dollars leveraged for housing	$0.00
HO04 - Banks made mortgage funds available to enable people to own their own homes	0
HO05 - Housing programs/policies created/improved	0
HO06 - Units of affordable, accessible housing made available	0
HO07 - People facilitated home ownership/rental	0
HO08 - People trained in housing	0
HO11 - Other	0
HO11 - Other	0
HO11 - Other	0

Section 3 Projects and/or Activities

Informing Public Policymakers re Housing Issu

Implementer:	✓ in house by contract/grant	Goal Area	Housing
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2009	Ending Date:	9/30/2014
Part B Funds:	$3,439.00	Other Funds:	$246.00
Intermediaries/Collaborators:	State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Maine Coalition fro Housing and Quality Services
b)
c)
d)
e)
f)
g)

Primary Activity Type

Coordination with Related Councils and Committees

Project Activity Description

Advocacy and training re housing issues included under the ME Disability Advocacy Coalition & Disability Leadership Institute sections. Focus on preventing HOME Fund depletion during budget hearings.

Section 3 Projects and/or Activities

Statewide Housing Conference

Implementer:	✓ in house by contract/grant	Goal Area	Housing
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	9/30/2010
Part B Funds:	$10,028.00	Other Funds:	$755.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) SUFU

b) Maine Parent Federation

c) Autism Society of Maine

d) Maine Coalition for Housing and Quality Services

e)

f)

g)

Primary Activity Type

Programs Barrier Elimination, Systems Design & Redesign

Project Activity Description

The Council is facilitating the planning for a series of workshops about the housing options for people with disabilities, the first of which is scheduled in December, 2009.

Section 3: Areas of Emphasis and Performance Targets

Quality Assurance

People have the information, skills, opportunities and supports to live free of abuse, neglect, financial and sexual exploitation, violations of their human and legal rights, and the inappropriate use of restraints or seclusion. Quality Assurance systems contribute to and protect self-determination, independence, productivity, and integration and inclusion in all facets of community life.

The MDDC has become a recognized resource for state policymakers, as evidenced by requests for info & input from legislators, as well as requests to chair workgroups to address specific legislative issues. The Legislature has requested that the MDDC provide an annual update on the status of Mainers with DD, including current concerns, barriers to access & waiting lists for services, strengths of current service systems, & recommendations for systemic change. The MDDC organized the Maine Disability Advocacy Coalition to coordinate advocacy activities on state and federal issues & has successfully mobilized this network to contact with state and federal policymakers, and to facilitate coordinated responses on key issues. MDDC provides information about upcoming legislation and hearings, other public policy concerns, initiatives and events, on a weekly basis to advocates, families and organizations via a series of listservs. 17 self advocates and parents have participated in the third class of the biennial Disability Leadership Institute. The strength of the program is evidenced by the activities and projects undertaken by participants & graduates; e.g. self advocates have become board members of nonprofit and advocacy organizations, including the Autism Society of Maine and an Aspergers� support group. The Advocacy Day program has been successful in providing an opportunity for novice and experienced advocates to meet at the Statehouse on a biweekly basis, learn about current issues, and meet with their legislators. The Council has participated in state workgroups to provide input into areas such as shared living rulemaking, guardianship, and quality improvement. The Council has monitored implementation of disability-related legislation, &took the lead in 2011 to draft changes to Maine statutes to eliminate the �R� word from all Titles. The Council has submitted legislative and rulemaking testimony on a variety of issues and supported advocates and self advocates in testifying. Finally, the Council has continued to support the state self advocacy organization and its growth to 14 local chapters and 274 meetings/conferences for self-advocates in FY11. MDDC continues to work on increasing the effectiveness of its own meetings, especially for parents and self advocates, and to be available to assist community members (in person, by phone or by email) with disability related questions/concerns by providing information or making appropriate referrals.

Quality Assurance – Self Advocacy

A. Is there a self-advocacy organization(s) in the state led by individuals with developmental disabilities, that receives direct funding from a private or public source?

Yes

B. Does the Council fund a self-advocacy organization lead by an individual with a developmental disability?

Yes

If yes, amount of funding Council contributes:

$76,100.00

C. Dollars leveraged for self-advocacy organization(s) in the state led by individuals with developmental disabilities:

$125,000.00

Outcomes in Quality Assurance

QA01 - People benefiting from quality assurance efforts of the Council	238
QA02 - Dollars leveraged for quality assurance	$126,770.00
QA03 - Quality assurance programs/policies created/improved	3
QA04 - People facilitated quality assurance	48
QA05 - People trained in quality assurance	1,150
QA06 - People active in systems advocacy about quality assurance	
Individuals with DD	234
Family Members	9
Others	0
QA07 - People trained in systems advocacy about quality assurance	
Individuals with DD	241

Others	3
QA08 - People trained in leadership, self-advocacy, and self-determination	1,700
QA09 - People attained membership on public and private bodies and other leadership coalitions	18
QA10 - Number of entities participating in partnerships or coalitions as a result of Council efforts	25
QA11 - Other	274
Number of local/statewide meetings for statewide self-advocacy organization and its chapters	
QA11 - Other	0
QA11 - Other	0

Section 3 Projects and/or Activities

Access to Information

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2006	Ending Date:	9/30/2011
Part B Funds:	$5,123.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Parent Federation
b) Southern Maine Parent Awareness
c) Autism Society of Maine
d) GEAR Network
e)
f)
g)

Primary Activity Type

Coalition Development & Citizen Participation

Project Activity Description

Council staff & members provide info & referral services when requested, & grants to self-advocates and/or parents to attend conferences and other activities that further the goals of the Council.

Section 3 Projects and/or Activities

All Maine Votes

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	11/30/2008
Part B Funds:	$0.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Association of Independent Neighborhoods
b) Speaking Up For Us
c) AbilityMaine
d) Alpha One
e) Brain Injury Association of Maine
f) Autism Society of Maine
g) Maine Center on Deafness

Primary Activity Type

Informing Policymakers

Project Activity Description

Work w/ other advocacy organizations & state policymakers to assure that all Mainers are able to vote, and to promote awareness of disability comm\'ty issues & candidates\' positions on those issues.

Section 3 Projects and/or Activities

ASD State Implementation Grant - Quality Assu

Implementer:	✓ in house ✓ by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2008	Ending Date:	8/31/2013
Part B Funds:	$0.00	Other Funds:	$1,623.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine State Department of Health and Human Services
b) Maine State Department of Education
c) Maine State Department of Labor
d) Autism Society of Maine
e) Maine Parent Federation
f) parents
g) self-advocates

Primary Activity Type

Interagency Coordination & Collaboration

Project Activity Description

Broad systemic change initiative - see project under Community Supports. Included under QA due to emphasis on including self-advocates & families in initiative.

Section 3 Projects and/or Activities

Assuring Effective Council Meetings

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2006	Ending Date:	9/30/2011
Part B Funds:	$88,865.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Council members

b)

c)

d)

e)

f)

g)

Primary Activity Type

Coalition Development & Citizen Participation

Project Activity Description

Council staff provide necessary materials/support to Council members, conducts public forums, & other activities to enable Council to be productive and effective.

Section 3 Projects and/or Activities

Disability Advocacy Day Program

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	2/1/2005	Ending Date:	9/30/2016
Part B Funds:	$7,792.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Speaking Up for Us
b) Statewide Independent Living Council
c) Maine Association of Interdependent Neighborhoods
d) Advocacy Initiative Network
e) community service providers
f)
g)

Primary Activity Type

Training

Project Activity Description

To promote/support increased involvement of consumers & family members, & disability community organizations, in development of public policies & funding important to achieving program goals.

Section 3 Projects and/or Activities

Disability Leadership Institute

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2005	Ending Date:	9/30/2016
Part B Funds:	$26,815.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Health and Human Services
b) Maine State Legislature and individual legislators
c)
d)
e)
f)
g)

Primary Activity Type

Training

Project Activity Description

Improve awareness of best practices in all emphasis areas and instruction/practice opportunities for people with DD and parents of children with DD to develop leadership & advocacy skills.

Section 3 Projects and/or Activities

Informing Public Policy Makers

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	10/1/2005	Ending Date:	9/30/2016
Part B Funds:	$13,436.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Equal Justice Partners
b) Maine Children\'s Alliance
c) Maine Advisory Council on the Education of Children with Disabilities
d) Autism Society of Maine
e) Maine Department of Health and Human Services
f)
g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Work collaboratively on public policy issues affecting persons with DD & their families. Provide information to state/federal policymakers on impact of pending policy decisions on persons with DD.

Section 3 Projects and/or Activities

MEDAC

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	12/1/2004	Ending Date:	9/30/2011
Part B Funds:	$16,521.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Equal Justice Partners

b) Ability Maine, The Advocacy Initiative Network

c) American Council of the Blind of Maine, Autism Society of Maine, Brain Injury Association of Maine

d) Learning Disabilities Association of Maine, Maine Center on Deafness

e) Maine Parent Federation

f) Maine Women\'s Lobby

g) Speaking Up for Us

Primary Activity Type

Coalition Development & Citizen Participation

Project Activity Description

Provide staff support & information to a coalition of disability advocacy groups to coordinate efforts to improve services & supports for people w/ disabilities at the state and federal levels.

Section 3 Projects and/or Activities

Respectful Language Usage

Implementer:	✓ in house by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2006	Ending Date:	9/30/2012
Part B Funds:	$667.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Speaking Up For Us

b) Brain Injury Association of Maine

c) Autism Society of Maine

d) Maine Department of Health and Human Services

e) Alpha One

f) Maine Center on Deafness

g) Iris Network

Primary Activity Type

Informing Policymakers

Project Activity Description

Educate policymakers & public re use of respectful language thru presentations & distribution of Put PEOPLE First brochure. Led work grp & completed rpt w/ recommendations for statutory lang changes.

Section 3 Projects and/or Activities

Speaking Up For Us

Implementer:	✓ in house ✓ by contract/grant	Goal Area	Quality Assurance
Grantee/Contractor Name (if appropriate):	Speaking Up For Us		
Beginning Date:	10/1/2003	Ending Date:	9/30/2016
Part B Funds:	$113,799.00	Other Funds:	$91,595.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System ✓ University Center(s) of Excellence		

Other Collaborators

a) Maine Department of Health and Human Services
b)
c)
d)
e)
f)
g)

Primary Activity Type

Coalition Development & Citizen Participation

Project Activity Description

Provide funding and assistance to further development of independent statewide self advocacy organization; and collaborate with SUFU in training and support for self advocacy.

Section 3: Areas of Emphasis and Performance Targets

Recreation

People benefit from inclusive recreational, leisure and social activities consistent with their interests and abilities.

The Council does not sponsor formal projects in the area of recreation at this time. However, opportunities to increase access to recreation is supported as as an outcome of other projects. The Council's contract with Speaking Up For Us, which offers regional conferences and local group meetings for individuals with developmental disabilities has approximately 20 local chapters, which hold regular monthly meetings, which also provide opportunities for socialization and recreation. The Disability Leadership Institute has provided opportunities for recreational relationships to develop between participants. Most performance measures are included in the numbers for Community Supports. The numbers for RE01 include 250 self-advocates who have participated in activities sponsored by Speaking Up for Us, and 10 children with developmental disabilities who had the opportunity to participate in a summer program offered by a community church, after training on inclusive programming was provided to the staff of the summer program through a grant from the DD Council. The church has documented the successful inclusion of children with DD in their summer program to share this information with other churches and church associations in Maine and other parts of the country.

Outcomes in Recreation

RE01 - People active in recreational activities through Council efforts	260
RE02 - Dollars leveraged for recreation	$0.00
RE03 - Recreation programs/policies created/improved	0
RE04 - People facilitated recreation	0
RE05 - People trained in recreation	0
RE08 - Other	0
RE08 - Other	0
RE08 - Other	0

Section 3: Areas of Emphasis and Performance Targets

Transportation

People have transportation services for work, school, medical, and personal needs.
The Council continues to hear from self-advocates & supporters this year about difficulty obtaining transportation. The concerns are focused in the following areas: lack of accessible transportation (in most areas of the state, including all rural areas); difficulty obtaining transportation across county lines (especially accessible transport), difficulty obtaining transportation to recreational activities & to activities that occur in the evening or on weekends. Agencies� interpretation of rules (in terms of what is a Mainecare-reimbursable service), budget cuts, & high fuel prices have resulted in decreased availability of transportation supports for social & recreational activities (esp on an individual basis) for those receiving Developmental Services. For those with DD who do not qualify for waiver services there has been an increase in the demand for transportation provided by community action & other programs. At the same time there has been a decrease in those volunteering to provide those services. The Council has participated in the Mainecare Advisory Committee on Transportation, whose charge is to identify problems encountered in the delivery of Mainecare-funded transportation & to make policy recommendations intended to improve access to & quality of transportation services. Because of the recommendations of this committee, transportation providers statewide are changing practices to increase access to same day transportation. The Council has continued to work with Maine Emergency Management Agency to hold regional workshops, during which the need to identify & plan for use of accessible emergency transportation has been stressed. A key point has been made that persons who have motorized wheelchairs or scooters must be transported with that equipment or if an emergency requires immediate evacuation and an accessible vehicle is not on-site, then prompt arrangements must be made to get the motorized equipment delivered to the individual after transport. As part of the trainings for self-advocates provided under the contract with the Council, Speaking Up For Us encourages individuals to seek informal supports to meet their transportation needs. As a result of that training, several SUFU members have been able to arrange for transportation provided by fellow church members and others in the community to participate in activities they are interested in attending, as well as to be able to go shopping, to the movies, etc.

Outcomes in Transportation

TR01 - People have transportation services through Council efforts	0
TR02 - Dollars leveraged for transportation programs	$0.00
TR03 - Transportation programs/policies created/improved	0
TR04 - People facilitated transportation	0
TR05 - People trained in transportation	0
TR08 - Other	0
TR08 - Other	0
TR08 - Other	0

Section 3 Projects and/or Activities

Informing Public Policymakers re Transportati

Implementer:	✓ in house by contract/grant	Goal Area	Transportation
Grantee/Contractor Name (if appropriate):			
Beginning Date:	1/1/2005	Ending Date:	9/30/2016
Part B Funds:	$1,416.00	Other Funds:	$0.00
Intermediaries/Collaborators:	✓ State Protection and Advocacy System University Center(s) of Excellence		

Other Collaborators

a) Speaking Up for Us

b) Alpha One

c) Brain Injury Association

d)

e)

f)

g)

Primary Activity Type

Informing Policymakers

Project Activity Description

Through support for Speaking Up For Us & Disability Advocacy Coalition work, and other collaborative efforts, support and join in advocating for solutions to transportation problems for PWD.

Consumer Satisfaction

Individual Survey Responses:

Total: 96

Respect (%): Yes 96.80% | No 3.20%

Choice (%): Yes 90.20% | No 9.80%

Community (%): Yes 94.70% | No 5.30%

Satisfaction (%): 61.10% 4 - Strongly Agree | 36.80% 3 - Agree | 1.10% 2 - Disagree | 1.00% 1 - Strongly Disagree

Better Life (%) : 53.10% 4 - Strongly Agree | 39.60% 3 - Agree | 3.10% 2 - Disagree | 4.20% 1 - Strongly Disagree

Rights (%) : Yes 93.80% | No 6.20%

Safe (%): Yes 97.60% | No 2.40%

Individual Comments:

When asked what was helpful: I learned new ideas how to spread awareness. // I learned about how to be a better self advocate.// Learning about the waiver services.// Learning about relationships.// I'm going to find out about benefits, with getting a job.// I learned more about Voc Rehab and what it can do for me.

Stakeholder Survey Responses

Total: 0

Choices and Control (%): 0.00% Strongly Agree | 0.00% Agree 0.00% Agree Somewhat | 0.00% Disagree Somewhat | 0.00% Disagree | 0.00% Strongly Disagree

Participation (%) : 0.00% Strongly Agree | 0.00% Agree 96 Agree Somewhat | 0.00% Disagree Somewhat | 0.00% Disagree | 0.00% Strongly Disagree

Satisfaction (%): 0.00% Strongly Agree | 0.00% Agree 0.00% Agree Somewhat | 0.00% Disagree Somewhat | 0.00% Disagree | 0.00% Strongly Disagree

Stakeholder Comments:

Stakeholders played a key role in development of the new State Plan for the Council, following up on initial input that they provided through a group meeting that was held in December, 2010. Comments from that meeting were included in last year's PPR.

Council Progress in Achieving Goals

Community Supports

Emphasis Area: Formal and Informal Community Supports **Goal:** Partially Met

MDDC has focused on advocacy efforts to reduce the effects of the State budget crisis on services for people with DD. Success has been measured, unfortunately, primarily in maintaining existing funding levels, rather than the addition of new funding to address the rapidly-growing waiting lists.
Those who have DD but do not meet eligibility criteria continue to have few service options. There is concern that recent rule & funding changes to children�s services are also limiting access to community supports. These continue to be critical issues that the Council has successfully raised to a high awareness level in the Legislature, but will continue to have to focus on due to the continuing economic ills in the State, and efforts to significantly reduce the DHHS budget. Self advocates have again been critically important to ameliorating proposed cuts to services, through the Council-supported statewide organization.
The Council also took a lead in assuring that persons with disabilities have played a key role in modifying emergency preparedness planning, to assure that the disability community is integrally involved in planning and monitoring of emergency services to provide appropriate and inclusive services. Emergency prep training has been completed across the state with the involvement of Council staff and the statewide self advocacy org.
The Council has been directly involved in specific efforts in the area of employment: Maine has completed its closure of sheltered workshops. Changes in the Community Support Waiver allow funds previously earmarked for dayhabilitation to be used for job supports with a concurrent decrease in unmet needs for employment supports. The wait list for VR services has been eliminated as VR has used stimulus money to end the queue. MDDC is closely monitoring changes in the VR intake process to determine whether people with very significant needs may be found ineligible. The Council has also been an active member ofthe Commission on Disability and Employment to address best practice in state employment & workforce development efforts. While improvements have been noted, the recession & state budget crisis are negative factors reinforcing barriers limiting the full employment of PWD; employment has been identified as a high priority for the Council and will require continuing efforts.

Education

Emphasis Area: Education and Early Intervention **Goal:** Partially Met

Educational services continue to be under severe stress. Systemic changes, including a significant increase in the numbers of children with Autism Spectrum diagnoses and changes in early intervention, are being dealt with in the midst of an ongoing fiscal crisis. Barriers include additional funding cuts to transition services, general and higher education, decreased access to case management, increased public perception that special education is a burden on taxpayers as well as a system that silos services related to education needs. The Council has involved more parents in the policymaking process this year, has increased access to technology to children with developmental disabilities, and has begun to address issues related to education of children with autism spectrum disorders.

People get and keep employment consistent with their interests, abilities and needs.

Emphasis Area: Employment **Goal:** Partially Met

The Council has been directly involved in specific efforts in the area of employment: Maine has completed its closure of sheltered workshops. Changes in the Community Support Waiver allow funds previously earmarked for dayhabilitation to be used for job supports with a concurrent decrease in unmet needs for employment supports. The wait list for VR services has been eliminated as VR has used stimulus money to end the queue. MDDC is closely monitoring changes in the VR intake process to determine whether people with very significant needs may be found ineligible. The Council has also been an active member ofthe Commission on Disability and Employment to address best practice in state employment & workforce development efforts. While improvements have been noted, the recession & state budget crisis are negative factors reinforcing barriers limiting the full employment of PWD; employment has been identified as a high priority for the Council and will require continuing efforts. The Council has begun work with the state Alliance for Full Participation team to address specific barriers to full of employment of persons with developmental disabilities.

Health

Accessibility of both physical and mental health care continue to be Council priorities. In 2009 the Council, in collaboration with DHHS, initiated a project to improve mental health services for people with developmental disabilities. A statewide task force is active and in total over 600 people have received training. Funding for this task force has been continued into FFY12, with a key goal to assure that future training, support and oversight are available to those providing services for persons with DD and mental health issues. Other barriers include a shortage of dentists and limited Medicaid coverage for adult dental services, overall lack of specialty providers that varies by geographic are), and a continued state financial crisis, which has resulted in restrictions in Medicaid coverage for home and community-based services for children with DD. The Council continues to work with the state agency and advocates to expand the availability of these services, and preserve the Katie Beckett option for children with DD who are otherwise ineligible for services that are available on a restricted basis primarily to Medicaid-eligible children. The state budget crisis is a barrier threatening the safety net of health care services, especially for people with developmental disabilities who are ineligible for services under the restrictive criteria used for access to developmental services. Planning for a project to address access in rural health centers is underway. Council funding and the federally-funded ASD grant have supported activities that have dramatically increased access to developmental screening by pediatricians, to promote earlier identification of ASDs in young children in particular, as well as access to appropriate and timely early intervention services.

Housing

Emphasis Area: Housing **Goal:** Partially Met

Economic barriers to increasing access to affordable housing chosen and controlled by persons with disabilities include: the recession, lack of funding and credit that limit development of creative housing options; lack of access to community supports limiting independent living; limited public housing/section 8 options w/ long & complex rules, no separate wait lists for accessible units. Systemic barriers to increasing access to affordable housing chosen and controlled by persons with disabilities include the fact that Maine has one of the nation�s oldest housing stocks and is overwhelmingly dependent upon oil for heating, making access & heating a challenge, as well physical & attitudinal barriers, including beliefs that persons with disabilities should live with others with similar diagnoses. The Council has heard from persons with disabilities, families & advocates who are concerned about the lack of information about generally available affordable housing options other than the family home or housing that is available through service providers. The Council has focused on sharing information about available options for financing housing alternatives, but considerable work remains to resolve the barriers to affordable and inclusive housing opportunities in Maine.

Quality Assurance

Emphasis Area: Quality Assurance **Goal:** Partially Met

Maine�s statewide self-advocacy organization (SUFU) continues to grow, to participate in policymaking at a on a wider variety of topics and levels and to support members to increase self-determination. With the Council's ongoing financial support in the annual contract with SUFU and other support provided by Council members and staff, the self-advocacy organization has developed into an independent non-profit organization, and continues to work on establishing a secure administrative structure for the future. There has also been a high level of participation in the Council�s leadership and advocacy education programs. Other Council activities include a focus on raising awareness of the rights of persons with developmental disabilities and the responsibility of public & private entities to make sure that they are inclusive in operation and practice.There is, however, growing concern that fiscal constraints and funding cuts are limiting programs that specifically foster community inclusion. At present evidence is anecdotal, with providers reporting that they are moving towards larger groups living together and more self advocates reporting financial constraints as reported barriers to their participation in statewide activities. Ongoing revenue shortfalls have resulted in growing wait lists and limitations in services, necessitating advocacy effort s to keep from losing ground rather than expanding or transforming services. This area of work will continue to be a high priority for the Council.

Transportation

Emphasis Area: Transportation **Goal:** Partially Met

Lack of available, accessible and flexible transportation options continues to be identified as a barrier to employment and full participation of persons with disabilities in their communities. Cuts to developmental service providers, along with high fuel prices, have limited transportation to include only what is �medically necessary�

and alternate transit has not translated into any measurable increase in options for persons with disabilities: Maine continues to rely very heavily on automobiles. People with developmental disabilities� access to transportation is limited by poverty, inability to drive, and lack of few accessible public transit options, especially across counties or for those who lack comprehensive waiver services. Although the Council has made limited efforts to address these issues, this was not an area that the Council's limited resources could significantly impact during the last few years.

Section 6: Reporting Year Expenditures

Type of Recipient	Sub Title B $	Other $	Total $
State Councils on DD	$343,454.00	$91,595.00	$435,049.00
Designated State Agency	$0.00	$1,898.00	$1,898.00
Other State Agency	$0.00	$22,062.00	$22,062.00
State P & A Agency	$0.00	$4,422.00	$4,422.00
University Centers for Excellence	$0.00	$33,666.00	$33,666.00
Non-Profit Organizations	$115,855.00	$31,992.00	$147,847.00
Others	$7,246.00	$270,856.00	$278,102.00
Total	$466,555.00	$456,491.00	$923,046.00

Areas of Emphasis	Sub Title B $	Other $	Total $
Employment	$13,683.00	$4,631.00	$18,314.00
Education & Early Intervention	$38,052.00	$100,163.00	$138,215.00
Housing	$3,439.00	$248.00	$3,687.00
Health	$87,725.00	$179,715.00	$267,440.00
Childcare	$0.00	$0.00	$0.00
Recreation	$0.00	$0.00	$0.00
Transportation	$1,416.00	$255.00	$1,671.00
Quality Assurance	$273,018.00	$140,048.00	$413,066.00
Community Supports	$34,351.00	$6,802.00	$41,153.00
General Management (Personnel, Budget/Finance/Reporting)	$14,871.00	$22,731.00	$37,602.00
Functions of DSA	$0.00	$1,898.00	$1,898.00
Total	$466,555.00	$456,491.00	$923,046.00

Dissemination of Annual Report

As of 2008, the Council is required to provide to the State Legislature the same information prepared for the Program Performance Report regarding status of persons with developmental disabilities, services and supports and systems capacity to address the needs of persons with DD. This provides the opportunity on an annual basis for the Council to present the annual report of its activities to the State Legislature and other policymakers. This information is also available on the Council's website, and is offered to the public at conferences and exhibits in which the Council is represented. The Council also provided a report of its activities at public meetings held throughout the state in fall 2010.

Section 8: DD Network Collaboration

Issue Identifier **Education services segregated, with continued use of seclusion and restraints.**

Description of Collaborative issue/barrier or expected outcome:

Education services for children with disabilities continue to be offered in segregated settings across the state, with increasing pressure to establish "regional programs" to reduce costs and consolidate resources. This would be a further retreat from the principles of inclusion in federal special education law. In addition, Maine state policies do not adequately address the issue of seclusion and restraints, and students are being inappropriately exposed to these practices.

Life Areas

Self-Determination
Employment
Housing
Health
✓ Education
Community Inclusion
Transportation
Childcare
Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

The Council continues to convene and facilitate the Maine Education Advocacy Alliance, with the P&A as a primary partner, to address issues that impact education services for children and youth with DD. The Council participated in FY11 in a task force created through the P&A's leadership to address the lack of regulations addressing the use of restraints and seclusion.

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Inadequate MH services for persons with DD**

Description of Collaborative issue/barrier or expected outcome:

Services for persons with dual diagnosis - intellectual disability and mental health disability - continue to be very inadequate, with few training opportunities and limited numbers of professionals in the DD and MH fields who have any cross-training.

Life Areas

✓ Self-Determination
Employment
Housing
✓ Health
Education
✓ Community Inclusion
Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

The Council continues to fund and facilitate the interagency Dual Diagnosis Task Force, which includes participants from both Network Partners. Through the participation of a national consultant on dual diagnosis issues funded by the Council, trainings have been made available in several locations in Maine to begin to expand service professionals' knowledge of appropriate services and supports for this population.

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Inadequate provider support for real inclusion of persons with DD**

Description of Collaborative issue/barrier or expected outcome:

Budget cuts are exacerbating the lack of available community-based services in integrated settings, with providers focusing on consolidation of services and greater segregation to reduce costs.

Life Areas

✓ Self-Determination
Employment
✓ Housing
Health
Education
✓ Community Inclusion
Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Lack of affordable, accessible housing**

Description of Collaborative issue/barrier or expected outcome:

Continuing lack of affordable and accessible housing/living options for persons with DD which foster independence and self-determination, and opportunities for community inclusion/integration.

Life Areas

Self-Determination
Employment
✓ Housing
Health
Education
✓ Community Inclusion
Transportation
Childcare
Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Lack of self-directed service options and support for self-determination**

Description of Collaborative issue/barrier or expected outcome:

Little information continues to be available to self-advocates and their families regarding guardianship options. Greater emphasis is needed in supporting self-determination for persons with DD, and educating families about ways to support independence.

Life Areas

✓ Self-Determination
Employment
Housing
Health
Education
Community Inclusion
Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Limited/narrow eligibility criteria for services for individuals with DD**

Description of Collaborative issue/barrier or expected outcome:

Maine has one of the most narrow definitions of DD for eligibility for home & community based services, resulting in individuals and their families going without services, or ending up in nursing homes or other inappropriate service facilities. This problem is exacerbated by the rapidly growing numbers of individuals with pervasive developmental disabilities, and the serious lack of capacity in Maine service systems to address the needs of persons with PDDs. This is reflected in growing waiting lists for waiver programs for those who meet DD services eligibility criteria.

Life Areas

✓ Self-Determination
✓ Employment
✓ Housing
✓ Health
✓ Education
✓ Community Inclusion
Transportation
Childcare
Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

The Council continues to work closely with the three state agencies, as well as the UCEDD and the state's P&A agency, the Autism Society of Maine, and others, to address the growing number of children and adults identified with autism spectrum disorders. The Council continues as the lead agency in coordinating the federal Autism Spectrum Disorders State Implementation Grant funded by HRSA. The Council also continues efforts to provide information to policymakers regarding the rights and needs of persons with DD, and the cost benefit of providing appropriate & effective community-based services for these individuals and their families, and works closely with the P&A in advocacy work on these issues.

Problems encountered as a result of collaboration:

Unexpected Benefits:

The interagency collaboration demonstrated as an integral part of the PDD Systems Change Initiative in 2008-2010 resulted in broader benefits to programs addressing the needs of persons with developmental disabilities, and the greater disability community. The selection of Maine to receive one of the ASD State Implementation Grants derived in large part from the work completed under the Council's PDD Systems Change Initiative, and has brought significant new federal funding to the state to address services for persons with PDD. Organized efforts focusing on services for persons with PDDs have resulted in changes/improvements affecting persons with other types of disabilities. An associated project funded by the Council to train primary care physicians in providing on-going medical care for children with PDDs has been built into the new ASD State Implementation Grant, and work is expanding to address training to support transitioning of young adults with PDDs to adult medicine practices.

Section 8: DD Network Collaboration

Issue Identifier **Oversight & evaluation of State Services for persons with DD**

Description of Collaborative issue/barrier or expected outcome:

The end in March, 2010 of the Consent Decree related to closure of Maine's state institution and creation of the community-based service system has removed court oversight of the DD service system. This is concurrent with rapid growth in the waiting lists for services for both waiver programs, and the State's fiscal crisis resulting in reductions in funding. There is significant concern about the potential for reductions in the quality and breadth of community-based supports for persons eligible for Developmental Services.

Life Areas

✓ Self-Determination
✓ Employment
✓ Housing
✓ Health
Education
✓ Community Inclusion
✓ Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

The Council collaborates with the P&A on a number of oversight activities, including working closely with the statewide self-advocates' organization, and oversight work of the Council itself. The Council is also a named member of the Oversight and Advisory Board created in statute in 2008 to evaluate services provided by DHHS for persons with ID or autism, and is leading an effort with the P&A to evaluate oversight responsiblities, and assure no gaps and avoid duplication.

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Persons with DD with physical functional limitations in nursing homes**

Description of Collaborative issue/barrier or expected outcome:

Continued lack of resources and service options have resulted in persons with physical disabilities being forced to live in nursing homes, often beginning in their teens and continuing into adulthood.

Life Areas

✓ Self-Determination
Employment
✓ Housing
Health
Education
✓ Community Inclusion
Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

The Council's Disability Leadership Institute provided advocacy training over the past three years for two people who were principal players in a recently-settled lawsuit that will allow individuals to move out of nursing homes and back into the community. One of those in the DLI was a parent who has been a leader in this fight, and the other, a self-advocate, has also become an active member of the DD Council.

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Rapid growth in waiting lists**

Description of Collaborative issue/barrier or expected outcome:

The state budget crisis, along with the increase in numbers of individuals with DD needing services, has resulted in rapid growth in the waiting lists for community-based waiver services. Even those individuals in crisis situations, at risk for health and safety, are on waiting lists for services, and state-funded crisis beds are filled to capacity most of the time.

Life Areas

✓ Self-Determination
Employment
✓ Housing
Health
Education
✓ Community Inclusion
Transportation
Childcare
✓ Quality Assurance
Recreation

Council Roles and responsibilities in collaboration:

Council representatives maintain an ongoing presence in the state budget discussions in the Legislature, as a vocal reminder of the need to address the growing waiting lists. The Council also monitors the size of the waiting lists, and receives per its request regular updates from the state agency regarding waiting list numbers, services being provided for those waiting for waiver openings, as well as unmet needs of those on the waivers. This information is in turn made available to the Legislature, and has influenced their deliberations, as evidenced by waiver program funds not enduring the same levels of reductions as other programs in the recent budgetary efforts to compensate for the State's economic downturn.

Problems encountered as a result of collaboration:

Unexpected Benefits:

Section 8: DD Network Collaboration

Issue Identifier **Support for Meaningful Self-Advocacy Involvement in policymaking activities**

Description of Collaborative issue/barrier or expected outcome:

Barriers continue to limit opportunities for persons with DD to participate in meaningful ways as self-advocates on boards, commissions & other work groups, and in other public policy arenas.

Life Areas

✓ Self-Determination
✓ Employment
✓ Housing
✓ Health
✓ Education
✓ Community Inclusion
✓ Transportation
Childcare
✓ Quality Assurance
✓ Recreation

Council Roles and responsibilities in collaboration:

The DD Council continues to fund and provide advice/support to Maine's statewide self advocacy organization, Speaking Up For Us. Through its Advocacy Day and Disability Leadership Institute programs, the Council provides opportunities for self-advocates to expand their skills and experience in participating in policymaking activities. The Council also supports the involvement of self advocates in public policy activities by providing support to other organizations in learning to provide necessary accommodations and in the adoption of inclusive practices/attitudes.

Problems encountered as a result of collaboration:

Unexpected Benefits:

The Maine State Legislature has been particularly welcoming of self advocates who attend the Advocacy Day program, and individual legislators have begun seeking out opportunities to interact with and learn from self-advocates about their views and concerns.

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
CHILD CARE									
CH03	Child Care Programs/policies created/improved	1	1	0	0	0	0	0	0
CH05	People trained in child care	0	60	14	0	0	0	0	0
CH06	People active in systems advocacy about child care	100	5	5	included under Quality Assurance				
COMMUNITY SUPPORTS									
CS01	Individuals receive formal/informal community supports	200	30	11	7,730	4,837	130	50	58
CS02	Dollars leveraged for formal/informal community supports	$0	$8,000	$0	$55,825	$47,421	$10,500	$0	$5,600
CS03	Programs/policies created/improved formal/informal community supports	0	0	6	19	5	8	2	2
CS04	People facilitate formal/informal community supports	100	15	0	0	0	0	1	5
CS05	People trained in formal/informal community supports	200	270	164	578	548	1,100	42	508
CS06	People active in systems advocacy about formal/informal community supports	0	430	430	included under Quality Assurance				
CS07	People trained in systems advocacy about formal/informal community supports	0	285	285	included under Quality Assurance				
CS09	Emergency Go-Bags distributed to Maine residents	n/a	n/a	n/a	3,014	3,600	40	0	0

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
	EDUCATION								
ED01	Students have the education & support they need to reach their educational goals through Council efforts		1	0	n/a	8	0	0	0
ED02	Infants & young children have the services/supports needed to reach developmental goals through Council efforts		0	0	n/a	70	1	0	0
ED03	Students transitioned from school to community and jobs		0	0	n/a	0	0	0	0
ED04	Children transitioned from early intervention and pre-school to inclusive schools/classrooms		0	0	n/a	0	0	0	0
ED05	People on waiting list(s) received services/supports		0	0	n/a	0	5	0	0
ED06	Dollars leveraged for education		0	0	$5,710	$30,456	$54,802	$49,000	$94,078
ED07	Education programs/policies created/improved		2	2	15	3	46	8	6
ED10	People facilitated inclusive education		0	0	0	0	0	0	4
ED11	People trained in inclusive education		60	200	280	98	226	380	475
ED12	People active in systems advocacy about inclusive education		30	30	included under Quality Assurance				
ED13	Parents trained regarding their child's educational rights		0	0	268	0	50	10	3

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
EMPLOYMENT									
EM01	Adults have jobs of their choice through Council efforts	0	0	98	59	118	65	0	29
EM02	Dollars leveraged for employment	$0	$0	$0	$0	$27,021	$0	$0	$0
EM03	Employers provided vocational supports to students on the job	0	0	0	0	0	0	0	0
EM04	Businesses/employers employed adults	270	0	0	0	2	0	0	0
EM05	Employment programs/policies created/improved	0	0	1	5	6	2	2	1
EM06	People facilitated employment	0	0	0	0	4	0	0	0
EM07	People trained in employment	270	50	0	0	17	88	50	13
EM08	People active in systems advocacy about employment	26	36	36	included under Quality Assurance				
EM09	People trained in systems advocacy about employment	26	38	38	included under Quality Assurance				

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
HEALTH									
HE01	People have needed health services through Council efforts	0	0	0	n/a	1,915	3,500	2,000	1,040
HE02	Dollars leveraged for health services	$0	$0	$0	$4,200	$1,211	$23,800	$49,000	$160,400
HE03	Health care programs/policies improved	10	3	2	4	1	5	21	23
HE04	People improved health services	0	1	0	0	0	4	0	14
HE05	People trained in health care services	0	0	264	463	602	622	547	472
HE06	People active in systems advocacy about health	2,070	265	265	included under Quality Assurance				
HE07	People trained in systems advocacy about health	50	54	54	included under Quality Assurance				
HOUSING									
HO01	Individuals have homes of their choice through Council efforts	0	0	3	1	1	1	5	6
HO02	People moved from congregate setting to homes in the community	0	0	1	1	0	0	0	0
HO03	Dollars leveraged for housing	$0	$0	$0	$0	$480	$300	$0	$0
HO05	Housing programs/policies created/improved	0	0	0	2	0	1	0	0
HO08	People trained in housing	0	0	15	0	17	0	75	0
HO10	People trained in systems advocacy about housing	0	8	8	included under Quality Assurance				

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
	QUALITY ASSURANCE								
QA01	People benefiting from quality assurance efforts of the Council	0	300	23	5,000	1,213	368	140	238
QA02	Dollars leveraged for quality assurance programs	$0	$0	$0	$0	$9,374	$132,000	$100,000	$126,770
QA03	Quality assurance programs/policies created/improved	1	1	1	17	3	8	1	3
QA04	people facilitated quality assurance	0	0	0	24	5	8	33	48
QA05	People trained in quality assurance	0	300	250	551	680	1,185	1,470	1,150
QA06	People active in systems advocacy	0	344	405	992	833	670	428	243
	self-advocates	-	-	193	186	186	320	264	234
	family members	-	-	47	691	33	300	122	9
	others	-	-	165	115	614	50	42	0
QA07	People trained in systems advocacy	200	100	498	352	651	1,180	264	255
	self-advocates	-	-	433	147	460	1,160	172	203
	family members	-	-	30	183	70	10	72	49
	others	-	-	35	22	121	10	20	3
QA08	People trained in leadership, self-advocacy, and self-determination	200	442	490	1,169	507	1,170	1,049	1,700
QA09	People attained membership on public and private bodies and other leadership Coalitions	-	45	17	11	19	75	15	18
QA10	number of entities participating in partnership or coalition created or sustained as a result of Council efforts	10	45	74	90	90	40	30	25
QA11	Other - meetings held for self advocates	-	-	-	196	354	190	182	274

Maine DDC Program Performance Report Data - FY04-FY11

	PERFORMANCE INDICATOR (partial list)	FY04 PPR Totals	FY05 PPR Totals	FY06 PPR Totals	FY07 PPR totals	FY08 PPR totals	FY09 PPR totals	FY10 PPR totals	FY11 PPR totals
	RECREATION								
RE01	People active in recreational activities through Council efforts	250	300	300	12	300	300	0	0
RE05	People trained in recreation	0	0	45	0	0	0	0	0
	TRANSPORTATION								
TR01	People have transportation services through Council efforts	-	0	11	12	32	0	41	0
TR03	Transportation programs/policies improved/created	-	2	1	1	0	0	0	0
TR04	People facilitated transportation	-	8	5	5	4	0	10	0
TR05	People trained in transportation	-	0	15	0	17	0	0	0
TR06	People active in systems advocacy about transportation	-	50	50	included under Quality Assurance				
TR07	People trained in systems advocacy about transportation	-	56	56	included under Quality Assurance				
	CROSS CUTTING								
CR01	Public policymakers educated by Council about issues related to Council Initiatives.	75	200	259	805	230	210	220	210
CR02	Copies of products distributed to policymakers about issues related to Council Initiatives	280	330	1,380	2,200	25	21	24	15
CR03	Members of the general public estimated to have been reached by Council public education, awareness and media initiatives.	150,000	30,000	185,000	122,911	70,000	190,000	179,420	294,900

Maine Developmental Disabilities Council

PROJECTS AND INITIATIVES
2010-2012

❖ *ADVOCACY AND EDUCATION FOR PUBLIC POLICYMAKERS*

In accordance with its responsibilities under the federal DD Act, the Council has provided ongoing information and support to legislators and other public policymakers in the development and review of proposed legislation, rules and other policies affecting persons with developmental disabilities and their families. The Council has provided information and participated in the revision of statutes and rules affecting civil rights, education, health care, employment, housing and other matters of concern to self-advocates, parents and other family members.

❖ *AUTISM SPECTRUM DISORDERS STATE IMPLEMENTATION GRANT*

The Maine Department of Health and Human Services has contracted with MDDC to manage a three-year grant award by the federal Health Resources and Services Administration, using funds from the Combating Autism Act Initiative. The grant is intended to improve health outcomes for individuals with autism and other Pervasive Developmental Disorders (PDDs) by identifying PDDs early, and providing effective, coordinate treatment and a longterm comprehensive medical home for each person with a PDD. Grant activities include development of a standardized screening process for young children utilizing existing resources, streamlining referral and access to early intervention services, expanding training opportunities for primary care physicians and other medical personnel to expand their capacity to provide high quality medical homes for their patients with PDDs.

❖ *CULTURAL COMPETENCE AND EQUAL ACCESS TO FAMILY SUPPORT SERVICES*

The Council is contributing financial support for an outreach project to family support services for families of children with disabilities in the Somali refugee community in Maine. This project, started in 2009, focused efforts on addressing the needs of this population, which has become increasingly important as the Somali population in Maine has expanded, with the Lewiston/Auburn area in Maine now the primary secondary resettlement area for this refugee group in the U.S.

❖ *DISABILITY ADVOCACY DAY*

Disability Advocacy Day is an ongoing activity organized by the Maine Developmental Disabilities Council in concert with other members of the Maine Disability Advocacy Coalition. This program provides an opportunity for self-advocates, family members, and other interested parties to become more familiar with the legislative process, and to take a more active role in communicating their concerns to their elected officials in the Legislature. MDDC provides advocacy training and makes arrangements for participants to meet with their senators and representatives personally at the State House and in their local communities. Individual participants in turn become mentors for others who wish to speak up for themselves about current issues affecting persons with disabilities, and organize ongoing connections with policymakers. Since 2007, more than 275 self-advocates, parents and provider agency staff have participated in this program.

❖ *DISABILITY LEADERSHIP INSTITUTE*

The Institute is a program for adults with developmental disabilities and parents of children with developmental disabilities who want to learn more about policymaking and legislative processes at the local, state and federal levels, and develop their knowledge and skills to participate effectively in those processes. This two-year program includes a series of two-day training sessions on a wide range of topics during which participants interact with representatives of public and private agencies and the legislature, and an independent advocacy-related project chosen by each participant for the second year of the program. Since 2006, 46 self-advocates and parents have participated in this intensive training program. Graduates have become involved in leadership roles in advocacy activities in their local communities and at the state level.

❖ *EMERGENCY PREPAREDNESS*

Since 2005, MDDC has been involved in providing regional training opportunities and materials for self-advocates, families and first responders to assure that the needs of persons with disabilities are addressed in emergency situations. Through MDDC efforts, more than 8,000 emergency "Go-Bags" have been distributed to individuals and families across the state. MDDC has been involved in outreach and training for state and local policymakers and other interested community members to promote the inclusion of persons with disabilities and their families in emergency planning and preparedness, and assurances that services are accessible and inclusive for all community members.

❖ *INTEGRATION OF CHILDREN WITH PDDS IN PRIMARY MEDICAL CARE OFFICES*

This project is designed to ensure that children with Pervasive Developmental Disorders (PDDs) are able to access quality health care in their local communities. The MDDC is providing funding for a pilot project conducted by two prominent developmental pediatricians in southern Maine to develop and test the use of a training curriculum for physicians and other staff in primary care medical offices. This training and ongoing technical assistance to primary care providers and their staff regarding assessment and medical care for children with PDDs is intended to promote the use of the "medical home" model for the ongoing care of these children.

❖ *MAINE DISABILITY ADVOCACY COALITION*

MDDC hosts and provides staff support for this coalition of more than 25 disability organizations to promote cross-disability awareness of the range of issues impacting people with disabilities and their families in Maine, and facilitate collaborative involvement in the development and monitoring of public policies and systems serving this population. MDDC publishes a weekly electronic report updating the status of legislation of interest to the disability community, and provides other information and presentations to support broader involvement and input in the development and monitoring of legislation and state agency rules and policies.

❖ *MAINE EDUCATION ADVOCACY ALLIANCE*

MDDC hosts and provides staff support for this alliance of six statewide organizations including: Maine Developmental Disabilities Council, Autism Society of Maine, Maine Parent Federation, Maine Transition Network, Disability Rights Center, and Learning Disabilities Association of Maine. This collaborative alliance has brought a unified and strong voice representing family concerns to public policy-making activities in the state legislature and executive branch. The Alliance encourages families to communicate with policymakers about their children's needs, and the impact of pending policy changes affecting their families. The Alliance and individual parents have been intensely involved in public policy activities related to special education laws and rules in Maine over the past four years, assuring a strong parent voice in the legislative and rulemaking processes.

❖ *PROMOTING ARTISTS WITH DISABILITIES*

The Council provides ongoing opportunities for persons with disabilities to display and market their artwork through collaboration with VSA Arts of Maine and the Center for Community Inclusion at the University of Maine, Orono. The Council provides space in its Augusta office at no cost for artists to display their work, and promotes their endeavors through periodic events to showcase new artwork and artistic competitions.

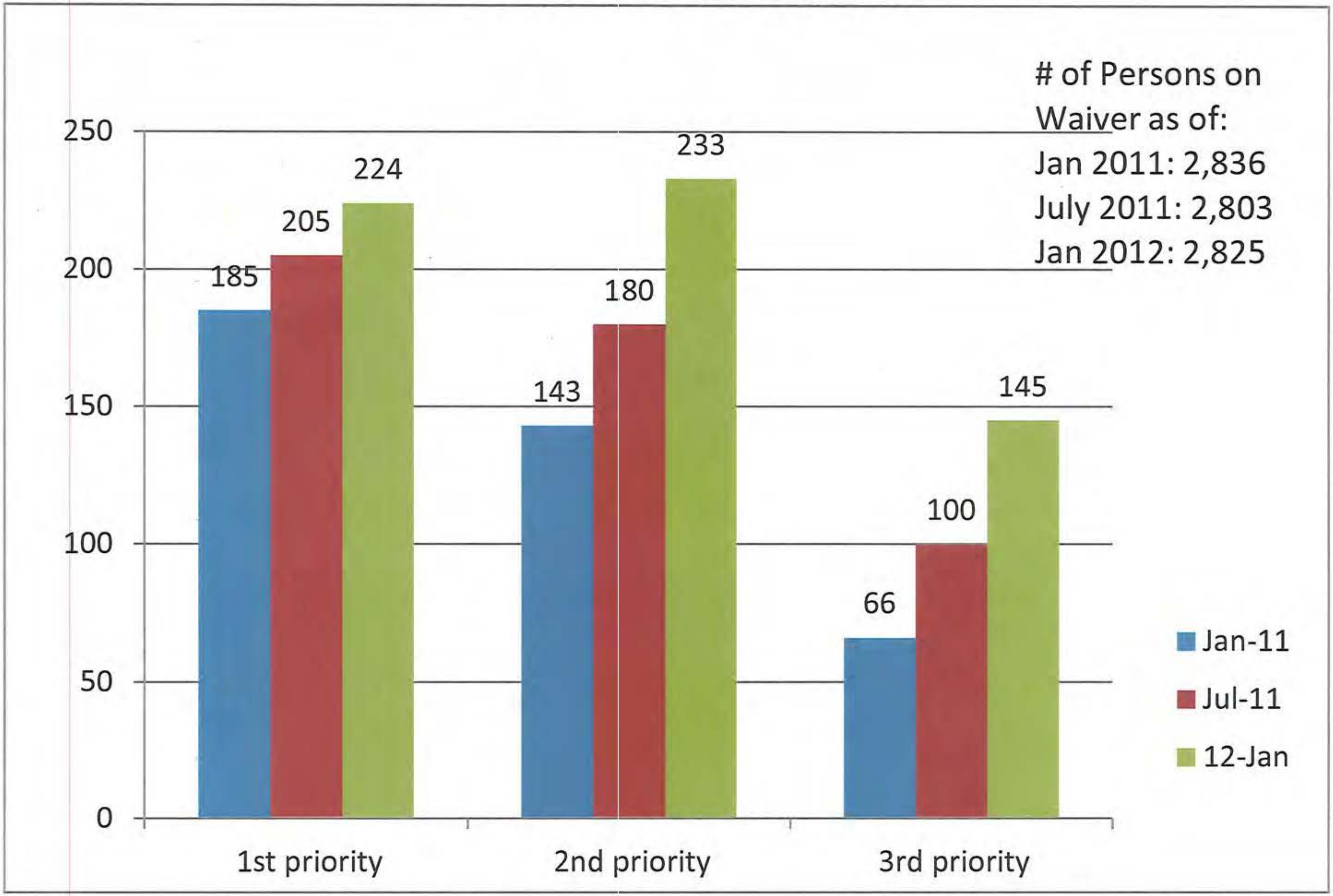
❖ *QUALITY MENTAL HEALTH SERVICES FOR PERSONS WITH COGNITIVE DISABILITIES*

MDDC is providing funding and staff support for a three-year project involving state and local agencies, self-advocates, family members and advocates in assessing current services, and determining and implementing needed systemic changes to improve the quality of mental health services for adults with developmental disabilities. Consultation by a national expert from the National Association for the Dually-Diagnosed and support for meetings of the interagency task force, as well as training opportunities for professionals in the targeted service systems across the state, are being supported primarily by Council funds, with additional support from the Offices of Mental Health Services and Developmental Services in the Maine Department of Health and Human Services.

❖ *STATEWIDE AND REGIONAL ORGANIZATIONS FOR SELF-ADVOCATES*

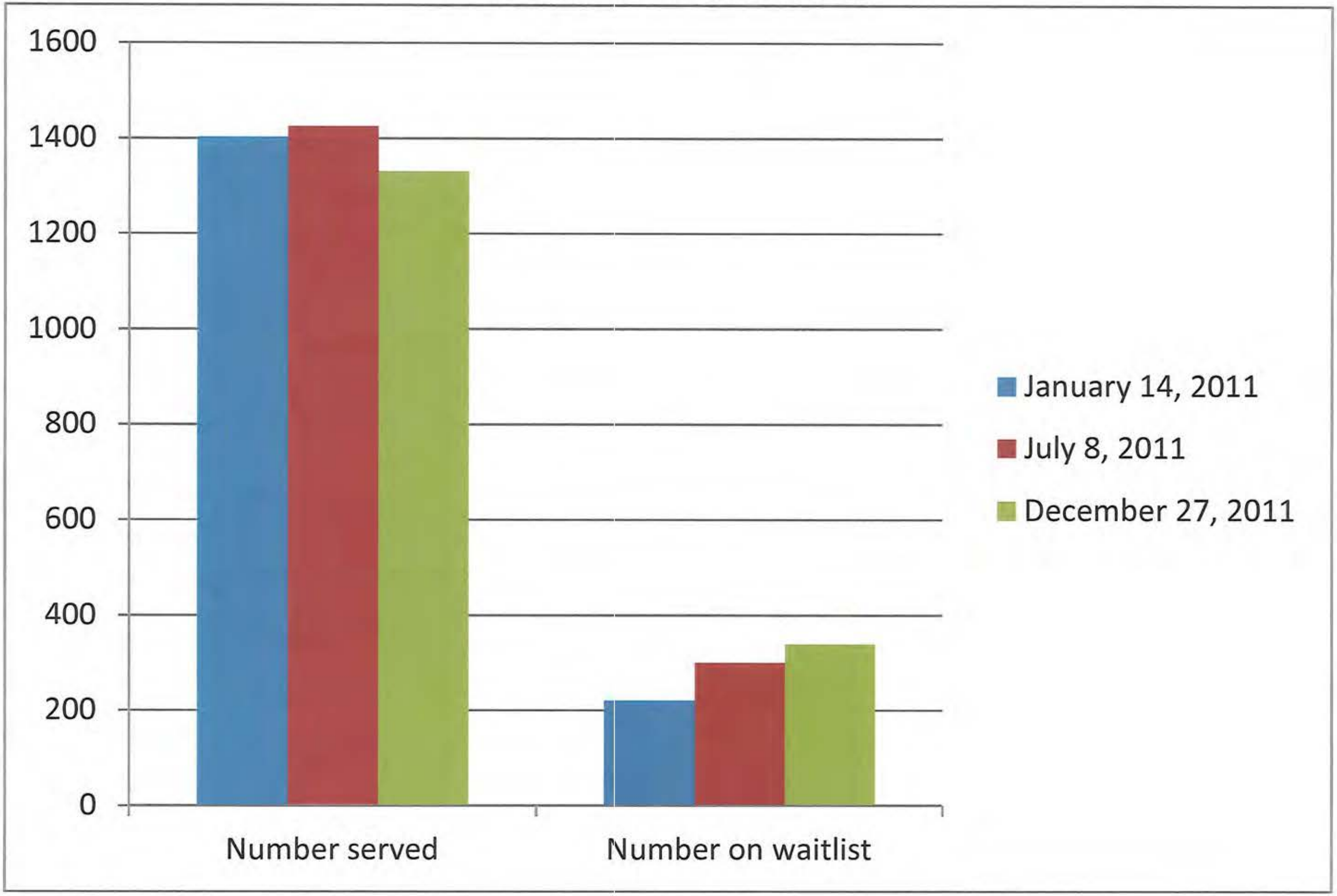
Through an ongoing contract and collaboration with Speaking Up for Us, a statewide self-advocates' organization for persons with developmental disabilities, the Council provides support for local groups and statewide events that offer training, networking and social activities, and encourage greater community involvement and inclusion. Presentations and trainings provided by representatives of this group in schools and other community settings also help to foster increased appreciation for the rights of persons with developmental disabilities, and their contributions to their local communities. In FY09 more than 1,100 people participated in training sessions provided under this contract, and more than 300 meetings were organized and run by self-advocates with developmental disabilities.

ADULT DEVELOPMENTAL SERVICES
SECTION 21 WAIVER
GROWTH IN WAITLIST IN LAST 12 MONTHS



DATA SOURCE: Maine Department of Health and Human Services, Office of Adults with Cognitive and Physical Disabilities Services

Adult Developmental Services
Section 29 Waiver
Growth of Waitlist in last 12 months



Data source: Maine Department of Health and Human Services, Office of Adults with Cognitive and Physical Disabilities Services

Waiting List Data provided by Maine DHHS

Waiting List Name	*FY 2002*	*FY 2003*	*FY 2004*	*FY 2005*	*FY 2006*	*FY 2007*	*FY 2008*	*FY 2009*	*FY 2010*	*FY 2011*
Adult's Services Waiting Lists										
Dev. Svs. Case Management (Adults)	199	133	109	0	🟥	🟥	🟥	🟥	🟥	🟥
Dev. Svs. Housing (Adults)	616	251	197	102	🟥	🟥	🟥	🟥	data not provided	334
Day Habilitation Funding (Adults)	304	170	14	0	🟥	🟥	🟥	🟥	🟥	🟥
Supported Employment Funding	215	330	187	156	180	138	114	🟥	41	54
Section 21 Waiver (Adult Svs.)	26	n/a	72	102	117	106	69	230	396	499
Section 29 Waiver (Adult Svs)	🟥	🟥	🟥	🟥	🟥	🟥	0	52	205	321
Community Employment - Adults (DD)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	104	41	93
Physical Disabilities HCBS Waiver - consumer-directed	🟥	🟥	🟥	🟥	72	96	113	108	112	73
VR Services	3-18 months	6 months	2064	2040	1248	1067	1418	1063	0	0

🟥 Indicates data no longer collected or not made available to MDDC

Prepared by Maine Developmental Disabilities Council January, 2012

Waiting List Data provided by Maine DHHS

Waiting List Name	*FY 2002*	*FY 2003*	*FY 2004*	*FY 2005*	*FY 2006*	*FY 2007*	*FY 2008*	*FY 2009*	*FY 2010*	*FY 2011*
Children's Services Waiting Lists										
Early Intervention Services	no report	no report	no report	no report	no report	43	63			
Assertive Community Treatment (CBHS)						11	9			
Outpatient Services (CBHS)	583	1061	869	894	811	272	n/a			
Medication Clinic (CBHS)	259	342	382	604	342	166	226			
Residential Treatment (CBHS)	22	51	0	7	12					
Home-based Family Services (CBHS)	219	200	165	151	178					
CSN Case Management	636	2	n/a	13						
In-Home Supports (CBHS)	922	30	250	44	4					
In-Home Supports (Children with DD)								18	51	59
In-Home Supports (Children with Behavioral Health Needs)								165	not available	
Targeted Case Management (Children)								136	52	14
Respite	156	22	274	4	no report	50	n/a			

Prepared by Maine Developmental Disabilities Council January, 2012

Office of Adults with Cognitive and Physical Disability Services
Developmental Services
Unmet Needs Summary Comparison
Data provided as of 6/30/2011
And as of December 2011

Need Area	**Number Unmet Needs as of 6/30/2011**	**Number Unmet Needs as of 12/2011**
Home Support	373	334
Community Support	234	47
Employment	87	54
Dental Services	77	53
Dental IV Sedation	29	23
Correspondent	28	28
Respite	23	11
Vision Services	15	16
Medical Services	13	12
Recreation Opportunity	13	7
Adaptive Equipment/Device	10	0
Environmental Modification	10	8
Other Personal Support	7	3
Funeral/Mortuary Trust	7	6
Hearing Exam	6	1
Occupational Therapy Service	6	5
Speech/Communication Service	6	4
Psychological Service	6	6
Behavior/Safety Plan	6	2
Volunteer Opportunity	6	0
Guardian/Rep Payee	6	4
Community Inclusion	3	7*
Physical Therapy Service	3	1
Counseling	3	5
Psychiatry	2	0
Legal Services	4	4
Transportation	4	1
Total	**987**	**635**

***this number assumes that "Recreation" is the same as "Community Inclusion" in the June, 2011 report**

The June 2011 report provided this additional information:

- The figures in the column above represent a point-in-time statewide summary of unmet needs as reported on 6/30/11 for persons served through Developmental Services programs.
- A total of 5369 individuals were enrolled in Developmental Services on that date.
- The unduplicated count of individuals with one or more unmet need is 713 or 13% of the enrolled population.
- As in previous snapshot summaries, Home Support, Community Support, Employment and Dental Services are the top five categories. Since 3/31/11, the unmet need for Home Support has increased by 11%, Community Support by 26% and Employment by 24%, while Dental Services has decreased by 12% and Dental IV Sedation Services has decreased by 22%.

Notes of this type were not included in the data sent to MDDC in December, 2011.

Copy provided to Health and Human Services Committee March, 2012

Maine Developmental
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(Information originally provided January 26, 2012 to Appropriations Committee members)

The information provided is related specifically to the proposals to

- establish an individual cap for the Section 21 waiver,
- eliminate the medical add-on for home supports, community supports work supports and employment specialist services, and
- eliminate case management services under the MaineCare State Plan.

1. PROPOSAL FOR INDIVIDUAL CAP OF $161,000 FOR SECTION 21 WAIVER

None of the information that the MDDC has examined suggests that this proposal will achieve the savings indicated in the supplemental budget proposal; rather, the cap may result in increased costs as many individuals whose costs of care exceed the $161,000 will likely require services in a more expensive setting.

MDDC staff were not able to find any other state that has chosen to apply an individual cap to its comprehensive services waiver. We looked in particular at other states that are comparable to Maine, having closed all publicly-funded institutions to serve individuals with intellectual disabilities and autism. As you will see later in this document, we have not yet found another state that uses an individual cap; all use the same type of aggregate cap that is currently in Maine's Section 21 waiver.

As reported to you late yesterday by the DHHS Commissioner and the Director of OACPDS, CMS has not responded affirmatively to either of Maine's questions about exceptions to the new cap:

a) Can individuals whose costs currently exceed $161,000 per year be "grandfathered", allowing them to continue to receive services at the current level?

b) Can Maine grant exceptions to the $161,000 cap, thus creating a "tiered" waiver?

From what we have been told by DHHS staff, it is unlikely that CMS will allow either of these to be part of the comprehensive waiver.

It is therefore especially concerning that the department has not provided any satisfactory explanation of what will happen to the individuals with higher costs if they cannot be served under the Section 21 waiver. To compound this issue, the proposed elimination of optional services, such as physical and occupational therapy, along with case management services, will result in additional costs charged to the waiver which may impact whether individuals are able to receive needed services and stay under the individual cap.

Data provided by DHHS to the Legislature in 2010 provided a breakdown of individuals being served and the budgeted amounts for each of those individuals for FY2010. The chart on the next page displays ranges of budgeted costs for services under the Section 21 waiver and the number of individuals receiving services whose costs were in each range during the 2010 fiscal year.

SECTION 21 WAIVER CLIENTS SERVED IN 2010

Cost Range of Budgets for individual cost of care for FY2010	Number of individuals in cost range	% of total waiver clients
$0-$24,999	185	6.63%
$25,000-$49,999	264	9.52%
$50,000-$74,999	413	14.42%
$75,000-$99,999	583	20.45%
$100,000-$124,999	475	16.82%
$125,000-$149,999	395	13.86%
$150,000-$174,999	237	8.29%
$175,000 - $199,999	100	3.53%
$200,000 - $224,999	96	3.35%
$225,000 - $249,999	30	1.06%
$250,000 - $274,999	23	.88%
$275,000 - $299,999	7	.21%
$300,000 - $324,999	11	.39%
$325,000 - $349,999	7	.25%
$350,000 - $374,999	2	.04%
$375,000 - $399,999	4	.18%
$400,000 - $424,999	3	.14%
TOTALS	2,835	

According to this data, fewer than one percent of the individuals on the waiver had budgets of over $300,000 as of the 2010 budget year, and approximately 10 percent (including those over $300,000) have budgets of $175,000 or more.

In considering that data, it is worthwhile to reference another report provided to the Legislature in 2005. That report provided information about a review of waiver clients with annual costs over $200,000 that had been completed by Clarence Sundram, Court Master for the Community Consent Decree, with DHHS staff. The summary of the review at the beginning of the report indicates:

> "...Overall the review teams were impressed with the efforts that agency staff made to provide stability, resulting in an improved quality of life. Approximately 75-80% of the cost associated with providing services to these individuals are for direct support staff. These individuals require intensive staffing for behavioral interventions and/or clinical supports..."
>
> "...Mr. Sundram reported that he was very impressed with the dedication and knowledge of the direct support staff. He also observed that, given the complexity of the individuals he reviewed, funds, for the most part, were well spent, perhaps resulting in an overall savings to the State by the dramatic reduction in costly, lengthy admissions to psychiatric hospitals. Mr. Sundram also commented that in any community system there will be some individuals who will be at a high cost to the State."

At the time of that report in 2005, 81 individuals had budgets of over $200,000, which the report indicates was 3.5% of the total being served on the waiver program. The 2010 data indicates that those with budgets of $200,000 or more totaled 183 individuals, or 6.4%. In relation to this increase in the percentage from 2005 to 2010, factors to be considered include:

a) While many of the new people going onto the waiver are young adults, others who have been on the waiver for longer periods of time are aging and have developed age-related health problems that increase their costs.

b) Since 2005, only individuals who have the most significant problems and are at highest risk for health and safety have been moved onto the Section 21 waiver. The complex needs of those individuals often cost significantly more to address.

As mentioned earlier, MDDC staff have looked for information about any other state which might have chosen to have an individual cap for the home and community-based waiver for persons with developmental disabilities. The table included with this document as Attachment A lists states which are all in comparable circumstances to Maine – they have closed all of their public institutions serving persons with intellectual disabilities and autism. This leaves each of those states and Maine without an institutional setting staffed by persons with the experience and training to provide the more intensive services that the "high cost" individuals would likely need. None of the five states or the District of Columbia has an individual cap associated with their Comprehensive Services Waiver program. (Note: the table includes information about Oregon's Supports Waiver, which has an individual cap as Maine does for the Section 29 waiver. The Oregon waiver application approved by CMS indicates that anyone whose costs will exceed the individual cap for the Supports Waiver is moved to the Comprehensive Services Waiver, which does not have a cap.)

We checked several more of the comprehensive waivers in a variety of other states, and found none of them to have an individual cap. It would be valuable information to consider if the department is able to provide some information about the experience of any other state that has adopted an individual cap for its comprehensive services waiver, or whether Maine is the first state to propose to do this.

2. PROPOSAL TO ELIMINATE TARGETED CASE MANAGEMENT SERVICES

Case management services play a vital role in assuring that:

- cost-effective services are available for individuals served;
- ongoing assessment of the quality of services being delivered is accomplished;
- unmet needs are identified and documented in a timely fashion; and
- program services encourage/promote greater independence and consumer management of resources.

Case managers can also facilitate innovative, cost-effective options that promote self-determination and less reliance on formal supports. One of the components that an increasing number of states are adding to their waiver programs is a self-directed option for management of resources, which promotes the goal of self-determination and is also more cost-effective.

Many individuals with developmental disabilities are capable of directing services themselves, others may have family members assist them, and some states are developing other models to support individuals in being able to self-direct services and manage resources. An example of this is the use of microboards, which had been implemented successfully in 20 states as of early 2010, with these boards in development in five other states.

Other states have created alternative models for provision of case management services. New Jersey has implemented a formal tiered case management system for persons with developmental disabilities. Under this system, "program case managers" have approximately 90 people on their caseloads, and provide services for people who are in structured service programs, through which there is regular oversight. Other people who are determined to be the "most vulnerable" received Primary Case Management, with caseloads for this service limited to 35 persons.

All of this information is explained in greater detail, along with other examples, in a Policy Research Brief prepared by the Research and Training Center on Community Living at the University of Minnesota. The policy brief summarizes their evaluation of models and best practices in case management in 20 states. The link to this document on-line is: http://ici.umn.edu/products/prb/191/default.html. The policy brief describes the critical role of case management services in facilitating access to services.

DHHS staff have provided additional information regarding the elimination of TCM which explains that individuals on the two Adult Developmental Services waivers will continue to have access to this service. This will require an amendment to the waivers. It is also important to consider the impact on potential savings being booked in the waiver account, as well as the impact on individuals, if State Plan services are eliminated and the costs of those services are transferred to the waiver. Adding in case management services as a waiver service contributes to each individual's total waiver costs; this may in turn threaten other services they need due to the individual cap.

As the table earlier in this document shows, more than 22% of those on the Section 21 waiver in 2010 had budgeted waiver expenses between $125,000 and $174,999. Some of the individuals in this range will already be over the cap of $161,000, but others may exceed the cap simply due to the addition of case management. (As mentioned earlier, this is further complicated by the potential elimination of optional services under the State Plan, resulting in those costs also being charged to the waiver for individuals who need these services.)

Even more problematic is the elimination of the current entitlement to case management services for those who are on the waiting lists for the two Adult Developmental Services waivers. With more than 940 individuals on the waitlists for the two waiver programs, the critical role of the case manager cannot be overemphasized. This support for these individuals and their families can help them to connect to other resources, assist in identifying specific needs, and determining who is at greatest risk for health and safety to assure they have earliest access to any openings on the Section 21 waiver. No information has been provided regarding how these responsibilities will be accomplished.

Attachment B to this document provides two charts that display the growing numbers of individuals on the waitlists – the current statutory entitlement to case management services assures these individuals and their families with some assistance in identifying other resources that may be available to them, which in turn may diminish the need for some waiver services or, at a minimum, provide some support while they wait for an opening on one of the waivers.

Data that MDDC has been tracking from the Department of Education indicates that there will continue to be a comparable number of students coming out of the school system each year who will meet the eligibility criteria for Adult Developmental Services. The data indicates that there has been a 111% increase in the number of students being served in the autism category in the schools in the last six years. According to national studies in this area, somewhere in the range of 45-60 percent of those students will be in need of longterm supports and qualify for Adult Developmental Services.

3. Proposal to Eliminate Medical Add-Ons in all settings

The Medical Add-On is more likely to reduce additional costs than consideration of addressing these needs through the State Plan, as was suggested during yesterday's work session. The Medical Add-On may pay the incremental cost of having a staffperson with more training and experience to work with an individual with specific medical needs. In other cases, it provides some additional funding to allow for existing staff to be trained and supported in addressing the needs of individuals with such needs. In either case, these are staff who also have expertise in providing the waiver supports that the person is otherwise in need of, whether that is support in employment situations, community activities or in the home.

As pointed out in the Appropriations Committee work session today, no savings accrue to the MaineCare program by simply transferring these costs to the State Plan, and in some cases the elimination of the medical add-on may increase costs or make it more difficult to find a provider able and willing to provide the needed services.

POTENTIAL OPTIONS TO REDUCE COSTS

The MDDC is concerned that the discussions this month regarding the Adult Developmental Services budget items has focused on whether individuals need to be served in residential settings with more beds, a move away from self-determination and inclusion that the waiver programs should be fostering.

More important to the current budget discussions, this discussion and a continued reliance on group residential settings contradicts what information from other States indicates will lower costs.

Many states have developed a variety of initiatives to make the best use of limited resources and address the needs of persons eligible for their waiver programs. While Maine focused on the development of group homes as it moved toward closure of Pineland, other states offered family support services and developed options such as shared living as alternatives to a much greater degree.

According to the 2011 edition of State of the States in Developmental Disabilities, published by the Coleman Institute for Cognitive Disabilities at the University of Colorado, Maine has the following ranking in types of residential supports for individuals with intellectual disabilities and autism:

Supported living/personal assistance services[1]	Maine is 29th in the United States in per capita spending	Maine's per capita spending for this service is $13.07; the national average for per capita spending is $21.16.
Out-of-home residential placements	Maine has the 9th highest percentage of individuals served in out-of-home community residential settings in the United States.	3,561 of 3,822 individuals served in 2009 were in out-of-home residential placements – 93% of total served.
Number of families caring for person with ID/autism in Maine receiving family supports from State	545 families receive support, of the estimated 11,750 families caring for a family member with ID.	Maine is one of six states in the country that provides support for only 5 percent or less of caregiving families.[2]

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[1] Supported living is defined for this study to include housing in which individuals choose where and with whom they live, in which ownership is by someone other than the support provider (such as the individual, family, landlord or housing cooperative), and the individual has a personalized support plan.

[2] At the other end of the spectrum, 18 states are estimated to provide family support for 20 percent or more of caregiving families.

Another way to look at the benefits of promoting models of support that enable individuals with intellectual and developmental disabilities to remain at home or live independently is in the table below:

STATE	% OF THOSE ON THE HCBS WAIVER SERVED IN SETTINGS OF THREE OR FEWER	AVERAGE COST PER PERSON
ARIZONA	96% in settings of 3 or fewer	$27,864
IDAHO	93% in settings of 3 or fewer	$31,802
NEVADA	98% in settings of 3 or fewer	$43,142
NEW HAMPSHIRE	94% in settings of 3 or fewer	$45,142
VERMONT	98% in settings of 3 or fewer	$55,341
MAINE	74% in settings of 3 or fewer	$86,657

Source of information: The Case for Inclusion 2011, An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities, published by UCP http://medicaid.ucp.org/download.php

OPTIONS THAT MAINE SHOULD FOCUS ON DEVELOPING:

1. Implementation of the Supports Intensity Scale to allow for effective allocation of resources to address individual needs.

2. A consumer-directed model for provision of services.

3. A broader array of supports included under the Supports Waiver than is currently part of Maine's Section 29 Supports Waiver, including Family Support, which can make a critical difference in enabling families to keep their family member who has an intellectual disability or autism living at home.

4. A stronger emphasis on Shared Living and other supports that can be provided at a lower rate than residential supports. (Current challenges to the administrative structure that Maine has established for providing Shared Living services should be addressed by examining the structures used in Vermont, New Hampshire, Rhode Island and other states, rather than simply deciding that Shared Living may no longer be a viable option in this state.)

Thank you for your careful consideration of the impact of the proposed cuts to people across Maine. The particular focus of this document is on people with developmental disabilities, but the issues that affect persons with DD and their families are shared by many others whose health status and capacity for living in and contributing to their local communities will be severely impacted by these cuts.

Please let me know if you have any questions about this information, or if further details would be helpful to you.

Thank you,

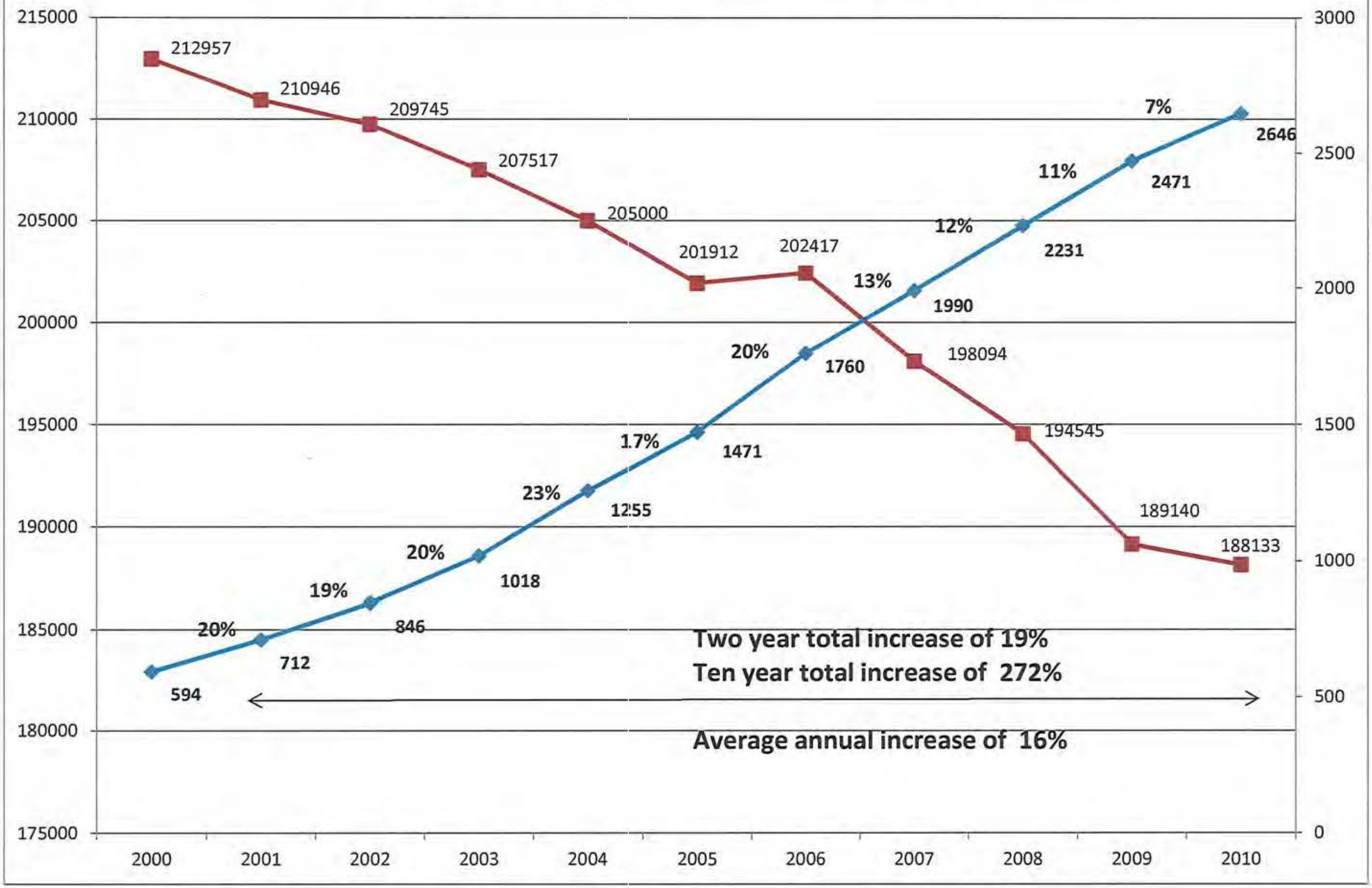
Julia Bell
Executive Director
Maine Developmental Disabilities Council

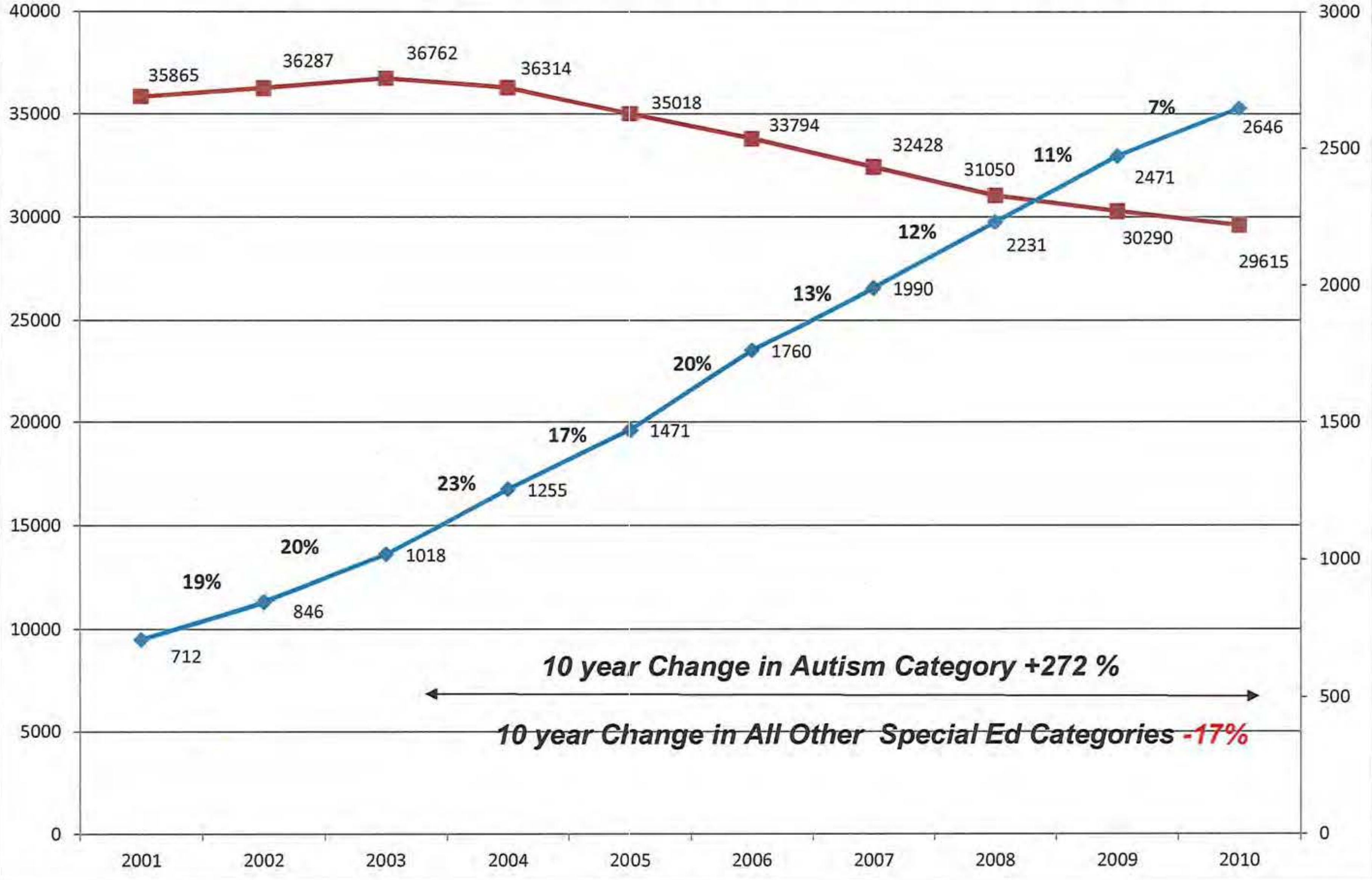
ATTACHMENT A

MEDICAID WAIVERS IN OTHER STATES

STATE	Waivers Serving Persons with DD	Medicaid Waiver Type	Individual Cap?	Calculation of allowable costs per person	Other info
ALASKA	Comprehensive Services Waiver	§1915(c) Home and Community-Based Services Waiver	**NO**	Aggregate cap – average per person costs must not exceed ICF/MR rate	Single waiver serves individuals of all ages with intellectual and developmental disabilities
DISTRICT OF COLUMBIA	Comprehensive Services Waiver	§1915(c) Home and Community-Based Services Waiver	**NO**	Aggregate cap – average per person costs must not exceed ICF/MR rate	
HAWAII	Comprehensive Services Waiver	§1915(c) Home and Community-Based Services Waiver	**NO**		
NEW HAMPSHIRE	Comprehensive Services Waiver	§1915(c) Home and Community-Based Services Waiver	**NO**	Aggregate cap – average per person costs must not exceed ICF/MR rate	
OREGON	Individual Supports Waiver	§1915(c) Home and Community-Based Services Waiver	**YES**	Individual Cap	Waiver indicates that anyone whose costs exceed the individual cap may be enrolled in the Comprehensive Services Waiver
	Comprehensive Services Waiver	§1915(c) Home and Community-Based Services Waiver	**NO**	Aggregate Cap – average per person costs must not exceed ICF/MR rate	
VERMONT	Global Commitment to Health Waiver	§1115 Waiver	**NO**	Aggregate cap – for ALL community-based longterm care services	Funding is allocated pursuant to Individual Service Plan, established procedure for application for additional funding

Comparative trends in the # of children served in Maine public schools under the category of Autism and total school population





Comparison of 10-year trends in # of Children Served in Maine Public Schools under the Autism Category and other Special Ed Categories

10 year Change in Autism Category +272 %

10 year Change in All Other Special Ed Categories -17%