

Massachusetts

Developmental

Disabilities

Council

FFY 2007 - 2011 State Plan



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1. Our Mission

The mission of the Massachusetts Developmental Disabilities Council is to provide opportunities for people with developmental disabilities and their families to enhance independence, productivity and inclusion.

❖ What We Believe

- ✓ Individuals with developmental disabilities must have the opportunity to live a full, productive and independent life in the community; and
- ✓ The greatest impact on public policy occurs through self-advocacy.

❖ What We Do

- ✓ Promote self-advocacy;
- ✓ Provide opportunities for people with developmental disabilities to impact public policy through self-advocacy;
- ✓ Promote activities that build the capacity of communities to provide opportunities for individuals with developmental disabilities to actively participate in community life;
- ✓ Promote system-wide changes that result in long-term positive impact on the capacity of individuals with developmental disabilities to lead meaningful lives in their home communities;
- ✓ Increase public awareness and work to eliminate the attitudinal barriers that impact independence, productivity, and inclusion;
- ✓ Foster and support coalitions with other advocacy and community groups; and
- ✓ Support close working relationships among and between the various public and private service providers.

2. Definition and Prevalence of Developmental Disabilities

The Federal definition of Developmental Disabilities is established by Public Law 106-402, "Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000" (42 USC 15001 et seq.). The Act describes a developmental disability as a severe, chronic, often lifelong disability that causes substantial limitations in several major life activities such as: self care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living, and economic self-sufficiency. It is attributable to a mental, emotional, sensory, and/or physical impairment that is apparent before the age of twenty-two. People with developmental disabilities often need a combination of special services, supports, and other assistance that is likely to continue indefinitely. Although the exact number is unknown, it is estimated that over 115,000 Massachusetts citizens have a developmental disability.

3. Role of the Developmental Disabilities Council

As reflected in our mission statement, a significant role of the Council is to provide opportunities for people with developmental disabilities to have a direct impact on the systems that affect their lives. By promoting the development of statewide self-advocacy organizations, and continuing support to groups such as Massachusetts Advocates Standing Strong and Families Organizing for Change, the Council provides more opportunities for individuals and families to impact public policy decisions. Additionally, the Council fosters collaboration among advocacy and community groups to enhance cross-disability coalitions leading to a stronger voice in disability advocacy. Ongoing legislative advocacy training opportunities contribute to a continuous expansion of the human resources available to educate policy makers. The Council's annual March legislative reception at the State House, bi-annual orientation for new legislators, and continued funding of various conferences, programs and publications helps to keep policy makers educated and focused on the important issues.

The Council also strives to enhance strong working relationships among and between state agencies, disability advocacy groups and service providers. The Council participates in a number of interagency boards, committees and task forces that address issues important to individuals and their families, and supports various demonstration projects that can lead to enhancing an individual and family centered system of community based services and supports for people with developmental disabilities.

4. Factors Impacting Inclusion of People with Developmental Disabilities

The following section provides a broad overview of factors that impact inclusion of people with developmental disabilities and issues that the Commonwealth faces in its efforts to enhance community based services and supports. This review is not intended to cover every issue and the Council recognizes that there may be other factors not covered here.

❖ **Cost of Living** - Massachusetts remains one of the most expensive states in which to live, significantly impacting the ability of individuals with developmental disabilities to live independently. From 2004 – 2005 housing prices in Massachusetts rose over 10% to a median cost exceeding \$350,000. The annual income needed to gain a mortgage to purchase an averaged priced home is well over \$100,000, and most people with developmental disabilities who are not supported in group home settings rely heavily on rental housing. This disparity also results in a greater reliance on subsidized housing and, as a result, the waiting list for subsidized rental housing in Massachusetts is extremely long. There is a severe shortage of decent, affordable housing for people with developmental disabilities, while federal and state funding for public and assisted housing continues to decrease. People with disabilities and advocates consistently rank the shortage of housing as one of the most significant needs in Massachusetts. It has been estimated from 2000 Census data that 59% of people aged 16 to 64 with disabilities work. However, the amount of working hours and the level of pay remain well below average for people with developmental

disabilities. Low wages combined with limited competitive employment opportunities for people with developmental disabilities in a high cost of living environment form a major barrier to establishing independence in the community.

- ❖ **Litigation** - A federal court found Massachusetts in violation of the federal Medicaid Act by failing to provide home-based services to an estimated 15,000 children with serious emotional disturbance, resulting in unnecessary confinement in residential facilities or in costly institutions far longer than their medical conditions require. The court ruled that the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services provisions of Medicaid require Massachusetts to provide Medicaid-eligible children with any services deemed medically necessary, whether or not the service is currently part of the Medicaid state plan. The judge cited the state's failure to provide adequate assessments, service coordination and home-based supportive services for children with serious emotional disturbances. The state is currently negotiating with plaintiffs' attorneys to determine proposed remedies and a timetable for implementation.

In June 2006 a preliminary settlement was reached between plaintiffs and the Massachusetts Bay Transportation Authority (MBTA). In 2002 a class action suit was filed in federal court alleging that the MBTA had discriminated against people with disabilities by denying them equal access to public buses and subway trains, in violation of Title II of the ADA and Section 504 of the Rehab. Act. The complaint alleged that the MBTA failed to maintain bus lifts, station elevators, subway stations and train platforms and other accessibility equipment in good operating, safe and accessible condition, and failed to ensure that bus and train operators provided proper service to passengers with disabilities. Under the settlement, the MBTA will comply with a number of requirements related to bus and subway operations, vehicle maintenance, station management, elevator access and communications with passengers.

- ❖ **Policy/Legislative Trends** – Despite continued cuts in service dollars at the federal level, and the difficulty in restoring past cuts at the state level, the trend toward increasing home and community based services and reducing institutional service settings is encouraging. Of the \$2.2 billion the state spends on long-term care each year, about \$1.6 billion is spent on 32,000 MassHealth enrollees who live in nursing facilities, at a rate of roughly \$52,000 per resident per year. The Commonwealth has undertaken an initiative to develop at least three new applications to Medicaid for waiver funding of home and community based services. The potential waivers include family support and related services, developing a waiver specifically directed for autism services, and a waiver to supplement the existing waiver for individuals who need supports to wrap-around state plan and generic services and require less than 24 hour residential services.

Two significant bills were recently passed that positively address community based services for people with disabilities. In April 2006 “An Act to Address the Special Education Needs of Children with Autism Spectrum” was signed into law. The law mandates that children with autism spectrum disorder receive equal educational

opportunities, and provides safeguards to insure that Individual Education Plans fully address their complex learning needs. In August 2006, the “The Equal Choices” law was also passed. The law is established to allow the elderly and people with disabilities to receive care in their homes, rather than in nursing homes, by changing MassHealth rules in favor of the redeployment of money spent on long-term care. This law underscores the principle that a community-based approach to care delivery is cost-effective and honors the preferences of elders and people with disabilities to remain members of the communities that they helped to build.

- ❖ **Eligibility** - The Department of Mental Retardation proposed new regulations which will change the way individuals are deemed eligible and are prioritized for services. The criteria used to determine eligibility appears designed to limit access to services, as the definition of “mental retardation” deviates from AAMR and other national definitions. Eligibility will be based on whether or not an individual has an IQ of 70 or below. Other organizations allow for flexibility or errors in measurement with a score range of 69-75. Secondly in determining eligibility (and later, priority for services), DMR will use their new MASSCAP tool to develop a “composite score” in regard to an applicant’s adaptive functioning. According to The Governor’s Commission on Mental Retardation, the criteria used by DMR in the definition of “Significant Limitations in Adaptive Functioning” is very stringent and not consistent with the definitions put forth by other established national professional organizations.

The new definitions and prioritization system will directly affect the amount and duration of services. The three prioritization categories into which an individual can be placed include community residential or 24hr services, community living supports and supportive services. Applicants will be assigned to these categories based on a “composite” score of adaptive functioning using MASSCAP. But the composite score may not capture the fact that someone has significant limitations in performing two or more of activities of daily living. The specific criteria for prioritization must be more transparent, citing how limitations in adaptive functioning will qualify or disqualify a person for the specific prioritization categories created by DMR.

- ❖ **Employment** - Despite some signs of progress, competitive employment opportunities for people with developmental disabilities continue to be limited. The majority of individuals with developmental disabilities are supported in facility-based employment programs (sheltered employment) and people with developmental disabilities participate in integrated employment at a lower rate than other disability groups. Community rehabilitation providers continue to offer a dual system of both integrated and sheltered employment options. Existing system and funding structures have not evolved, nor new structures developed, that will foster more competitive employment opportunities and a greater variety of employment options for people with developmental disabilities. A greater investment in program and support staff is also needed to assist individuals with developmental disabilities to develop career plans and to guide them through the potential impact of work income on benefits. In addition, opportunities for individuals with developmental disabilities to continue their education beyond high school is critical for improved employment opportunities.

School districts and institutions of higher education need to establish partnerships to offer concurrent enrollment programs for students with disabilities. The state recently provided funds in the FY 07 budget to establish a pilot program at the state colleges and universities. The pilot directs the Department of Education and the Board of Higher Education to develop guidelines to support college and work opportunities for people with disabilities.

- ❖ **Education** – In early 2005 the Department of Education issued proposed changes to Chapter 766 (special education) regulations to bring them in line with federal changes. Many of the proposed changes would have resulted in a significant limitation of the rights and protections afforded to students and families. The department argued that the proposed changes were in line with the reauthorization of IDEA, but after considerable advocacy and pressure from the state legislature, the department agreed to withdraw the proposed changes until the final IDEA regulations were promulgated. With the recent issue of the new IDEA regulations, it is anticipated that proposed changes to Chapter 766 regulations will be issued in the near future.

The creation of the Division of Autism within the Department of Mental Retardation provides the state with an opportunity to better serve the rising number of students diagnosed with autism and autism spectrum disorder. The Autism Division serves children ages 3 – 18 who have a Pervasive Developmental Disorder, including Autism, Rett's Syndrome, Asperger's and others as defined by the DSM-IV Revised Edition. The division currently leads the coordination across agencies, provides professional training and disseminates information to families through Autism Support Centers. However the state is in the process of developing an application for a home and community-based services waiver under section 1915(c) to allow eligible children with autism spectrum disorder to receive waiver services to support them in their homes and communities. It is expected that the application will be finalized early in calendar year 2007. In addition, the division received a significant increase in funding from \$1.2 Million to \$3.0 Million in the FY 07 state budget.

5. Areas of Need and Opportunities for Inclusion

People with developmental disabilities and families have underutilized the natural supports that exist within their communities. The traditional service system tends to isolate individuals from the rest of the community and fails to utilize generic community resources. There is a need to continue educating communities about the needs and contributions of people with developmental disabilities, and to encourage the development and/or adaptation of existing resources to meet those needs. Service providers, both state and private, need to encourage integration not only to develop an ongoing support system for individuals, but also to provide opportunities for people to be valued members of their communities.

In July 2002, Chapter 171 of the Laws of Massachusetts, An Act Providing Support to Individuals with Disabilities and Their Families, was passed. The purpose of the law is

to make the statewide policy and practice for flexible individual and family supports responsive to the needs of people with disabilities and their families. Effective implementation of Chapter 171 has proven to be difficult. The main issues are that the agencies responsible for developing plans do not see the law as pertaining to individuals served outside of the family context, and the 'substantial consultation' requirement has been narrowly defined. Funding for flexible supports through the Department of Mental Retardation and the Massachusetts Rehabilitation Commission remains limited, and no other agencies provide any significant supports. Efforts must be made to encourage agencies to embrace the spirit and intent of the law. Massachusetts has piloted numerous projects addressing self-determination and flexible supports. The state has received and implemented several federal pilot systems change projects designed to enhance self-directed support opportunities for people with developmental disabilities, including the Mass. Medicaid Infrastructure project, Real Choices, Independence Plus, the Community Personal Assistance Services and Supports (CPASS) project, and the recently awarded Systems Transformation project. Although many of these initiatives have included pilot projects designed to show the benefits of self-directed supports, the results of these pilots have yet to translate into any long-term systems change to support self-determination. More people with developmental disabilities should benefit from flexible support services.

More than 2,400 individuals were identified to receive services from the Department of Mental Retardation (DMR) as the result of a settlement agreement approved in U.S. District Court in 2001. The agreement resolved a federal class action lawsuit related to the DMR Waiting List, and a total of \$114 million (\$85 million in new appropriations) was mandated by the settlement to address the waiting list over a five-year period from 2001 - 2006. After FY2006 however, the state is no longer mandated to provide any funds under the terms of the settlement. While the Commonwealth made a commitment to provide significant funding to serve people on waiting lists and those entering the system, there are no future guarantees. There is no longer any legal mandate in place to compel the administration or the legislature to provide any funding for services to new individuals. And the state no longer maintains a definitive waiting list for services, as it was essentially the existence of a waiting list that led to Boulet lawsuit.

The Commonwealth is in the process of developing at least three new applications to Medicaid for waiver funding of home and community based services. The potential waivers include family support and related services, developing a waiver specifically directed for autism services, and a waiver to supplement the existing waiver for individuals who need supports to wrap-around state plan and generic services and require less than 24 hour residential services. In addition, the Governor recently signed two significant bills into law designed to positively address community based services for people with disabilities. However, while waivers and related legislation can increase the numbers who are eligible to live in the community, community inclusion remains an unattainable goal if individuals with developmental disabilities and their families are unable to determine their own needs and direct the services and supports that they receive. The struggle remains to gain the commitment and momentum needed to move from policy to practice.

In recent years a number of self-advocacy organizations led by individuals with disabilities have emerged, but have struggled to be heard and recognized as significant players in the shaping of public policy. In order for individuals with developmental disabilities to ultimately have control, choice and flexibility in the services and supports they receive, they must have the capacity to engage in meaningful and productive self-advocacy and the ability to define the types of services and supports they want and need. Self-advocacy organizations must become as sophisticated as professional advocacy organizations, and must link their efforts with other organizations striving for similar outcomes.

6. Process and Rationale for Council Goal Selection

Continued federal allotment reductions dictate that the Council must implement more efficient and effective organizational strategies. During FFY 06 the Council conducted a review of its organizational structure and operational methods. Through this review the Council determined that it must limit the number of areas that it addresses in the State Plan, and that the best strategy for maximizing impact is to place a stronger emphasis on policy development and implementation. Beginning in FFY 07, Council staffing and grant resources will be realigned to effectively implement this strategy. The Council also recognized that its strongest asset is the trust that it has developed with both the disability advocacy community and public policymakers. The successful partnerships that have been established over many years have reinforced the Council's position as a facilitator and consensus builder, and the Council is in a unique position to coordinate policy initiatives that will enhance a consumer and family centered system of community based services and supports for people with developmental disabilities.

The Council values the perspective of all stakeholders and relies on them to help determine the priority of needs. After conducting stakeholder interviews, research and analysis, the Council established a survey tool for stakeholders to use to prioritize the issues. The results of the survey were used to assist the Council in establishing State Plan goals and objectives. In addition to self-advocacy and leadership development (required by the DD Act) the top priorities identified by stakeholders were community inclusion, flexible supports and education/transition.

Through a long-term partnership with MA Advocates Standing Strong, the statewide self-advocacy organization for people with developmental disabilities, the Council has assisted many people to gain self-advocacy, systems advocacy and leadership skills. This partnership has provided opportunities for self-advocates to be more actively involved in policy development at both the local and statewide level. It is critical that the Council continue to foster leaders through its partnership with M.A.S.S. in order to establish people with developmental disabilities as the leaders of tomorrow, and the Council will continue to support the Self-Advocacy Leadership Series developed under the previous plan, with a focus on developing more trainers. The Council has been the primary source of financial support to M.A.S.S. for the past six years. Both organizations recognize the need to establish M.A.S.S. as a self-sustaining entity, and will need to work in partnership to achieve this outcome over the next five years.

People with developmental disabilities need flexible supports to enable them to live in and meaningfully participate in their communities, and there is a continuing need to address the bureaucratic barriers to self-direction. The planned expansion of waiver services and recent legislation to shift resources to the community and to improve individual and family supports provides a great opportunity for the Council to work toward enhancing community inclusion and flexible supports. There is also an opportunity to expand services and supports to address the needs of people with developmental disabilities who are un-served. To effectively achieve this, the initiative must also focus on the housing, employment and education barriers that impact people's ability to lead independent lives.

Students with developmental disabilities face numerous barriers to receiving the education they need to effectively transition to adult life. Families and advocacy groups are concerned about the impact that the regulation changes resulting from the reauthorization of IDEA and anticipated changes in state Department of Education regulations will have on a student's ability to succeed in school. There is a great challenge ahead to insure that the rights and protections for students and their parents are not diminished, and to establish opportunities for students to continue their education beyond high school.

7. FFY 2007 – 2011 State Plan Goals and Objectives

❖ Employment

Goal 1: People with developmental disabilities will have more employment options.

Objective 1.1: More people with developmental disabilities will work in integrated employment settings.

❖ Education

Goal 2: People with developmental disabilities will successfully transition to adult life.

Objective 2.1: More people with developmental disabilities will have the education and support they need to reach their educational goals.

Objective 2.2: More people with developmental disabilities will participate in post secondary education.

❖ Housing

Goal 3: People with developmental disabilities will choose where and with whom they live.

Objective 3.1: More affordable/accessible housing options will be available for people with developmental disabilities.

❖ Self Advocacy/Leadership

Goal 4: Self-advocates with developmental disabilities will have choice, control and independence in their lives.

Objective 4.1: More people with developmental disabilities will gain the skills needed to be strong self-advocates.

Objective 4.2: More people with developmental disabilities will become leaders in systems advocacy.

Objective 4.3: The statewide self-advocacy organization will achieve financial self sufficiency.

❖ **Community Supports**

Goal 5: People with developmental disabilities and families will have the level and quality of services and supports they need to lead full, productive and independent lives in the community.

Objective 5.1: State agencies will implement Chapter 171 (Flexible Supports Law) to the letter and spirit of the law.

Objective 5.2: More people with developmental disabilities and family members will benefit from flexible support services.

Objective 5.3: More people with developmental disabilities who are un-served will have access to appropriate community services and supports.

❖ **Public Awareness/Policy Education**

Goal 6: Policymakers and the general public will support people with developmental disabilities to live independently in the community.

Objective 6.1: Improve the education of policymakers about issues related to the Council's State Plan initiatives.

Objective 6.2: More members of the general public will be educated about the Council's State Plan initiatives.

8. Strategies to Implement the State Plan

The Council undertakes numerous activities to effectively implement the State Plan. Specific strategies for Plan implementation vary by objective. The types of activities as required by the DD Act include:

- ❖ Outreach
- ❖ Training
- ❖ Technical Assistance
- ❖ Supporting and Educating Communities
- ❖ Interagency Collaboration and Coordination
- ❖ Coordination with Related Councils, Committees and Programs
- ❖ Barrier Elimination, Systems Design, and Redesign
- ❖ Coalition Development and Citizen Participation
- ❖ Informing Policymakers
- ❖ Demonstration of New Approaches to Services and Supports

In addition to collaborative efforts with public and private partners, the Council awards sub-grants to numerous organizations to support the Council's efforts to meet the outcomes identified in the State Plan Objectives.

9. Federal Performance Measures

In addition to the State Plan goals and objectives, the Council identifies quantitative performance measures under specified federal Areas of Emphasis. These measures are used to determine the Council's success in meeting its goals and objectives, and progress is reported to the federal Administration on Developmental Disabilities on an annual basis. The following performance measures have been identified for the 2007 – 2011 State Plan.

❖ Employment

Adults have jobs of their choice through Council efforts.
Dollars leveraged for employment.
Businesses/employers employed adults.
Employment programs/policies created/improved.
People facilitated employment.
People trained in employment.

❖ Education and Early Intervention

Students have the education and support they need to reach their educational goals through Council efforts.
Students transitioned from school to community and jobs.
Dollars leveraged for education.
Education programs/policies created/improved.
Post-secondary institutions improved inclusive education.
Schools improved IEP practices.
People facilitated inclusive education.
People trained in inclusive education.
Parents or guardians trained regarding their child's education rights.

❖ Housing

Individuals have homes of their choice through Council efforts.
People moved from congregate settings to homes in the community.
Dollars leveraged for housing.
Housing programs/policies created/improved.
Units of affordable, accessible housing made available.
People facilitated home ownership/rental.
People trained in housing.

❖ Quality Assurance (Self-Advocacy/Leadership)

People benefiting from quality assurance efforts of the Council.
Dollars leveraged for quality assurance.
People trained in quality assurance.

People active in systems advocacy (all Areas of Emphasis).
 People trained in systems advocacy (all Areas of Emphasis).
 People trained in leadership, self-advocacy, and self-determination.
 People attained membership on public and private bodies and other leadership coalitions.
 Number of entities participating in partnerships or coalitions as a result of Council efforts.

❖ **Community Supports**

Individuals benefit from formal/informal community supports as a result of Council efforts.
 Dollars leveraged for formal/informal community supports.
 Formal/informal community supports programs/policies created/improved.
 People facilitated formal/informal community supports.
 People trained in formal/informal community supports.

❖ **Public Awareness/Policy maker Education**

Public policymakers educated about issues related to Council Initiatives.
 Copies of products distributed to policymakers about issues related to Council Initiatives.
 Members of the general public estimated to have been reached by Council public education, awareness and media initiatives.

10. FFY 2007 State Plan Budget

Cost Categories - Areas of Emphasis	Part B Federal Funds	Non-Federal Matching Funds	Total
Employment	\$112,236	\$24,817	\$137,053
Housing	\$112,236	\$24,817	\$137,053
Education and Early Intervention	\$242,328	\$53,582	\$295,910
Self-Advocacy/Leadership	\$242,282	\$53,572	\$295,854
Community Supports	\$270,330	\$59,774	\$330,104
Cost Categories – Administrative	Part B Federal Funds	Non-Federal Matching Funds	Total
10. General management	\$358,615	\$79,294	\$437,909
11. Functions of the Designated State Agency	\$0	\$0	\$0
12. TOTAL FFY 2007	\$1,338,027	\$295,856	\$1,633,883

11. Additional State Plan Copies

This State Plan may be copied and distributed by any individual or organization that chooses to do so, or additional copies may be requested from the Council. For additional copies contact:

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12. Council Membership

The Massachusetts Developmental Disabilities Council is comprised of thirty-three volunteer members and a small staff. Citizen members are appointed by the Governor for terms of up to three years, and include individuals with developmental disabilities, family members or guardians of people with developmental disabilities, professionals and advocates. Additional representatives from state disability agencies and the developmental disabilities network programs are appointed by their commissioners and directors. If you are interested in a member appointment to the Council, contact us at number above to obtain more information and an application.