

Massachusetts

Developmental

Disabilities

Council

FFY 2001 ANNUAL PROGRAM
PERFORMANCE REPORT



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

The Massachusetts Developmental Disabilities Council is comprised of twenty-eight volunteer members and a small staff. Members are appointed by the Governor for up to three-year terms, and include individuals with developmental disabilities, family members or guardians of people with developmental disabilities, professionals, advocates, and representatives of state and private service agencies.

The Council believes:

- ✓ 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.

The Council supports these beliefs by:

- ✓ Promoting self-advocacy;
- ✓ Providing opportunities for people with developmental disabilities to impact public policy through self-advocacy;
- ✓ Promoting activities that build the capacity of communities to provide opportunities for individuals with developmental disabilities to actively participate in community life;
- ✓ Promoting 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;
- ✓ Increasing public awareness and working to eliminate the attitudinal barriers that impact independence, productivity, and inclusion;
- ✓ Fostering and supporting coalitions with other advocacy and community groups;
- ✓ Supporting close working relationships among and between the various public and private service providers.

WHAT ARE DEVELOPMENTAL DISABILITIES?

Although the exact number is unknown, it is estimated that over 108,000 Massachusetts citizens have a developmental disability. A “developmental disability,” as defined in federal law, is 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. People with developmental disabilities constitute the most severely underserved population in the Commonwealth.

THE STATE PLAN

The Council develops a State Plan every three years that includes goals and objectives to address the most important issues affecting people with developmental disabilities. Priorities are established through the input from people with developmental disabilities and their families. The Council's success is measured by both its ability to achieve the outcomes established by the State Plan, and the real impact that these outcomes have on the lives of people with developmental disabilities and their families.

THE ANNUAL REPORT

The FFY 2001 annual report is a synopsis of the activities of the Council from October 2000 – September 2001. The outcomes indicated were generated from numerous initiatives undertaken to meet the State Plan objectives. These initiatives were implemented through our partnerships with the disability advocacy community, various grants and contracts awarded by the Council, and through the collaborative activities undertaken with our DD Partners, the University Affiliated Programs and the Protection and Advocacy Agency.

FFY 2001 STATE TRENDS

The most significant development impacting people with developmental disabilities is the downturn in the economy. The state has predicted a \$1.4 Billion budget shortfall for SFY 2002. Human service programs were hard hit in the recent state budget. However effective advocacy has led to restoration of many of the cuts, and the Governor has included additional resources in the recently filed supplemental budget for SFY 2002. It is anticipated that this reprieve will be short-lived, as expectations for SFY 2003 suggest more cuts are on the way. Although the connection between the disability and employment communities has improved significantly, the prospect of a weakening economy will significantly impact the availability of jobs. Beginning in January 2002, the special education standard will change from the state standard of "Maximum Feasible Benefit" to the federal standard of "free and appropriate education." It is anticipated that this change and others enacted last year eliminate or reduce many of the services essential to the well being of youth with developmental disabilities. Considerable efforts have been made to improve housing options for people with developmental disabilities. Partnerships between disability groups and generic housing agencies have led to some unique strategies for housing options. The limited housing market however, remains the largest barrier. The recently settled nursing home and waiting list lawsuits provided that approximately 4000 people with developmental disabilities would receive appropriate community services and supports over the next six years. Although initial budget cuts jeopardized the state's ability to meet the settlement requirements, the targets for this year will likely be met. Meeting the targets in later years could prove difficult however. In July Governor Swift announced the formation of an Olmstead Planning Task Force. The Task Force began work in September, with public hearings held in the fall. It is anticipated that the initial Olmstead Plan will be completed by June 2002. An unanticipated benefit of the cross-disability summit held in November 2001, has been the strong participation by people of all disabilities in the Olmstead hearing process, and this has been very effective in helping to shape the direction of the Plan.

COUNCIL ACCOMPLISHMENTS

Self-Determination

State Plan Goal: Support self-advocates to address universal disability issues.

FFY 2001 Outcomes

3,692 people have control, choice and flexibility in the supports they receive through Council efforts

5,827 people on waiting list(s) received services/supports

\$5,755,000 dollars were leveraged for self-determination

25 self-determination programs/policies were created or improved

168 people facilitated self-determination

28 people attained membership on public and private boards

254 people received Council training in self-determination

1,590 people were active in systems advocacy about self-determination

280 people were trained in systems advocacy about self-determination

136 people were involved in services/supports evaluation and quality assurance activities

The Gopen Fellowship supported a parent to learn policy issues from the DD network partners and to work on cultural diversity in DD. Fifty self-advocates were supported to participate in the SABE National Self-Advocacy Conference. One parent was sponsored to participate in a national training on legislative advocacy and empowerment. The Council established a partnership with the statewide self-advocacy organization and supports its capacity building initiative. The Council collaborated with its DD partners to host the first ever cross disability summit to establish a consumer mandate for the future of services and supports for people with disabilities in MA. An analysis of all state budget line items impacting people with DD was completed for all three state budget documents. People with DD, families and legislators utilize these resources in their successful budget advocacy efforts. The Council sponsored an annual reception to provide a forum for hundreds of people with DD and families to present their legislative and budget priorities, and to visit with their legislators. Legislative and budget advocacy skill training was provided to individuals and families, and TA on organizational development and strategic planning was provided to community groups. The Council continued support to the Disability Policy Consortium to enhance member leadership skills and to plan for self-sufficiency. The Council supported the Capacity Interchange project to assist minority agencies to develop supports for people with DD and families. The Council collaborated with the MR and elder services agencies to establish a cross-agency Elder Task Force, conducted an Elder Caregivers Outreach project, and worked with HESSCO Elder Services to establish local MR/Elder coalitions in five communities. The Parent Advocacy project provided a family advocate to work with families on accessing local community resources. A booklet on estate planning for parents and family members was republished and disseminated. The Council participated on the Statewide Independent Living Council and on the Coalition for Legal Rights to educate the community on legal issues impacting individuals with DD.

Employment

State Plan Goal: Increase the employment of people with developmental disabilities.

FFY 2001 Outcomes

162 Adults have jobs of their choice through Council efforts

\$210,424 dollars were leveraged for employment programs

102 businesses/employers employed adults

2 employment programs/policies were created or improved

82 people facilitated employment

1,560 people received Council training in employment

24 people were active in systems advocacy about employment

8 self-advocates and family members were trained in systems advocacy about employment

In partnership with the State Human Resources Division, the Council provided training and technical assistance to state agencies to support the hiring of people with developmental disabilities in state and municipal government. The Council also participates on the Employment Services Action Council, working with state human service agencies to develop community based employment options for people with developmental disabilities. Collaborative efforts with the Governors Commission on Employment continued to promote employment in the public and private sector, and included the establishment of the Business Leadership Network in MA. The Council served on the MA Partnership for Transition, a public-private project providing information sharing and networking to coordinate the increase of employment opportunities for youth and young adults with DD. In partnership with the Northeast Independent Living Program the Council developed an action plan for implementing career development systems change based on a previous assessment of best practices in inclusive career counseling and transitional planning. Support was provided to the MA Business Leadership Network to develop Internet based resources providing employers easy access to a pool of qualified candidates with DD, and to provide information and resources on successful employment to people with DD. In collaboration with Community Work Services the Council established an applied assistive technology (AT) lab that utilizes AT to facilitate integration, educational and employment objectives for people with DD. In addition, the Council provided use of its offices as a training site for people with DD entering the workforce. The Council continued to advise the Institute for Community Inclusion on strategies to enhance services and supports to people with developmental disabilities. In partnership with the state mental retardation agency the Council conducted a press campaign, educated Chambers of Commerce on hiring people with DD, and conducted its annual public awareness billboard campaign to promote employment of people with DD. This year's theme included a woman with DD winning a race with the slogan "Hire a Winner".

Housing

State Plan Goal: Expand housing opportunities for people with developmental disabilities.

FFY 2001 Outcomes

30 individuals have homes of their choice through Council efforts

42 people on waiting list(s) received services/supports

350 people moved from congregate settings to homes in the community

\$2,745,514 dollars were leveraged for housing

5 banks made mortgage funds available to people with developmental disabilities

5 housing programs/policies were created or improved

86 units of affordable, accessible housing were made available

19 people facilitated home ownership/rental

339 people received Council training in housing

285 people were active in systems advocacy about housing

722 people were trained in systems advocacy about housing

The Council collaborated with ARC Massachusetts to conduct housing seminars tailored to meet the needs of specifically targeted communities. In conjunction with seven Family-to-Family support centers the project also provided personalized assistance to individuals with developmental disabilities and families in their housing searches. The Council supported the development of an interactive web site for the Mass Access housing registry to provide people with DD direct Internet access to available housing. The project included beta testing by people with DD and public awareness activities to increase use of the site. The Council collaborated with United Cerebral Palsy of Metro Boston to conduct research on alternatives to traditional housing models for people with DD. The project recommended models for providing flexible, on-going housing support to people with DD. The Council successfully advocated for continuation of the Home Modification Loan Program, originally funded through a Council supported bond bill. Release of bond funds must be authorized each year. The program provides \$2 Million per year for home access modification loans. In partnership with the Cape Organization for the Rights of the Disabled, a local project to develop housing that incorporates independent living models for people with developmental disabilities was initiated. The project works directly with local public officials to meet the housing needs of people with developmental disabilities. In addition, the Council supported the Citizen's Housing and Planning Association to undertake a multifaceted campaign to increase housing through capacity building for Section 8 homeownership, training for housing professionals, outreach and marketing, and updating a housing resource guide. The Council supported a conference on home ownership opportunities for people with DD focusing on strategies to enhance ownership in a tight housing market, and participated in the Home of Your Own program to provide down payment assistance to people with DD seeking to purchase homes. This project included individualized assistance from home buying counselors.

Health

State Plan Goal: Improve the quality of health services provided to people with developmental disabilities.

FFY 2001 Outcomes

335 people have needed health services through Council efforts

\$2,353,437 dollars were leveraged for health services

16 health care programs/policies were created or improved

69 people improved health services

9,356 people received Council training in health care services

1,148 people were involved in systems advocacy on health care

1 Personal Care Attendants Bill of Rights was passed

The Council supported New England Index to establish a statewide resource list of dentists providing services to people with DD on the MA Network of Information Providers (MNIP) database. This project, with an emphasis on identifying dentists who accept Medicaid, provides an accessible method for individuals and community agencies to identify local dentists. Through the Coalition for Managed Care Quality the Council educated policymakers on health care issues impacting people with DD and their families. In collaboration with the Association for Community Living a curriculum, training materials and protocols were developed to assist people with DD, families and hospital personnel to effectively collaborate in serving and supporting people in hospital settings. The curriculum was published as a training manual for health care professionals. The DD Substance Abuse project organized partnerships for supporting and serving individuals with DD abusing alcohol and/or drugs within the community and criminal justice systems. Community Partnerships, Inc. has begun expanding partnerships for supporting individuals through dissemination of and technical assistance on utilizing the "Blueprint for Community Solutions". As a member of the Massachusetts Health Council, the DD Council worked with the administration and Legislature to improve health care services to citizens of MA. The Council collaborated with the Tufts University Dental School to develop an innovative curriculum to provide general dentistry students with the knowledge, perspective and skills to treat people with DD in private practice settings. The second phase of this project targets redesign of the logistics of patient treatment to improve the capacity of the Tufts Dental School to provide comprehensive dental care to people with DD. The Council also partnered with Tufts School of Medicine to incorporate disability related content into the core curriculum of its Family Medicine Clerkship. People with DD will be hired and trained to serve as "standardized patients", in simulated interviews and feedback sessions with medical students. The Council supported the Coalition for Patient Confidentiality, working for passage of House Bill 2310/Senate Bill 479, An Act Protecting the Privacy of Medical Records.

Education

State Plan Goal: Improve educational opportunities for children and young adults with developmental disabilities.

FFY 2001 Outcomes

39 students have the education and support they need to reach their educational goals through Council efforts

22,119 infants and young children have the services/supports needed to reach their developmental goals through Council efforts

35 people on waiting lists received services

\$5,710,031 dollars were leveraged for education

7 education programs/policies were created or improved

25 people facilitated inclusive education

140 people were trained in inclusive education

The Council participated on the Early Intervention Interagency Coordinating Council assisting the Department of Public Health to plan, develop and implement policies and practices for early intervention services, including the preparation of applications under Part C and compliance monitoring activities. The Council partnered with the Association for Community Living to provide education and assistance to middle and high school students with DD and their families residing in rural areas of western Massachusetts, focusing on preparation for transition to adulthood. The project conducted group training, mentoring, educational advocacy and case management. Second year activities focused on after-school activities, one-to-one training, parent training and continued educational advocacy. The Council continued to advise the Shriver Center UCE on strategies to enhance services and supports to people with developmental disabilities. Last year, under Special Education Reform, the Legislature changed the special education standard from "maximum feasible benefit" to the federal standard of "free and appropriate education". In collaboration with the Massachusetts Advocacy Center, the Council initiated a project to train parents, attorneys and advocates about the recent revisions to Chapter 766 (the Massachusetts special education law), the impact of the law and the responsibilities of students and families. The Council also participated on the Education Law Task Force of the Special Education Coalition to provide information and networking opportunities for students, parents, advocates and attorneys around special education issues. As a follow-up to initial Council funding, the Federation for Children has translated information on special education laws and rights into Portuguese, and conducted numerous family training sessions.

Community Inclusion

State Plan Goal: Expand support services for people with developmental disabilities and their families.

FFY 2001 Outcomes

448 individuals are valued, participating members of their communities through Council efforts

3,058 people on waiting list(s) received services/supports

\$21,337,523 dollars were leveraged for community inclusion

63 community inclusion programs/policies were created or improved

1 building/public accommodation became accessible

403 people facilitated community inclusion and participation

1,035 people received Council training in community inclusion

1,257 people received Council training to prepare for managed long-term supports

4,262 people were active in systems advocacy about community inclusion

935 people were trained in systems advocacy about community inclusion

124 people were educated about managed long-term supports

The Council supported individuals with DD and family members to attend conferences and related events to support their self-determination activities and enhance self-advocacy skills. Norwell Public Schools created an infrastructure within the school and community recreation systems to support the inclusion of students with DD in after school and weekend recreation activities. Year two activities include expanding the project to additional school districts. In collaboration with the MA Rehabilitation Commission, the Council initiated a project to develop an innovative network of transportation supports for students with DD. The project links transportation resources to career planning activities. The LINKS program was developed to promote self-sufficiency and the strengthening of Latino families of people with DD by facilitating access to and participation in community leadership opportunities. The Council established a partnership with Horace Mann Educational Associates and the League of Women Voters to develop and implement a curriculum to educate people with DD about local government and strategies for addressing issues with public officials. The Council advocated with the administration to develop an Olmstead Plan, and also led an initiative to establish a coalition of cross-disability advocacy organizations to insure effective consumer participation in the development of a comprehensive plan for Massachusetts. The Council started the Conference Supports Funds Program to provide stipends for registration fees to individuals with DD and families for conferences specifically targeting self-determination and self-advocacy. The Council utilized a web site and quarterly newsletter to educate the community and policy makers on current disability issues in MA and on the efforts of the Council on behalf of people with DD.

Cross Cutting Activities

FFY 2001 Outcomes

876 public policymakers were educated about issues impacting people with developmental disabilities

12,194 copies of products produced through Council initiatives were distributed to policymakers

3,127,000 members of the general public were reached by Council public awareness activities

Educating policymakers is a major focus of most Council initiatives. The Council collaborated with its DD partners to hold the first ever cross disability summit to establish a consumer mandate and educate policymakers on the future of services and supports for people with disabilities in Massachusetts. The state budget analysis was completed for all three state budget documents and people with DD, families and legislators utilized these resources in their successful budget advocacy efforts. The Council sponsored an annual reception to provide a forum for hundreds of people with DD and families to present their legislative and budget priorities, and continued its support to the Disability Policy Consortium in their efforts to educate policymakers. The Council participated on the Coalition for Managed Care Quality, educating policymakers on health care issues impacting people with developmental disabilities and their families. The Council also participated on The MA Health Council board. A dozen major publications and many smaller documents were produced and disseminated to policymakers through Council supported projects. The Council conducted its annual public awareness billboard campaign to promote employment of people with DD. This year's theme included a woman with DD winning a race with the slogan "Hire a Winner". The Council collaborated with the state MR and rehabilitation agencies, the Governor's Commission on employment and other entities in numerous public awareness and education activities. In addition, the public awareness efforts of many Council projects included articles in newspapers and other local publications.

FFY 2001 Council Expenditures

A. Types of Recipient

RECIPIENT	Part B \$	Match \$	TOTAL
1. DD Council	\$322,836	\$0	\$322,836
2. State Agencies	\$11,040	\$151,987	\$163,027
3. P & A System	\$31,126	\$0	\$31,126
4. UAP	\$15,000	\$8,376	\$23,376
5. Non-Profit Organizations	\$255,870	\$229,750	\$485,620
6. Other	\$499,984	\$51,120	\$551,104
7. TOTAL	\$1,135,884	\$441,232	\$1,577,116

B. Cost Categories – Priority Areas, General and DSA Functions

CATEGORY	Part B \$	Other(s) \$	TOTAL
1. Employment	\$95,730	\$154,299	\$250,029
2. Child Development	\$0	\$0	\$0
3. Community Living	\$155,668	\$92,509	\$248,176
4. System Coordination	\$657,688	\$122,146	\$779,834
5. General Management	\$226,759	\$72,278	\$299,077
6. TOTAL	\$1,135,884	\$441,232	\$1,577,116