

Massachusetts Developmental Disabilities Council

Five Year State Plan

For year 2014

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Section I : Council Identification

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

PART B: Contact Person: **Daniel Shannon, Executive Director**

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PART C: Council Establishment:

(i) Date of Establishment: **1971-Jan-01**

(ii) Authorization: **Executive Order**

(iii) Authorization Citation: **Executive Order 512**

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

(i) Council Membership rotation plan:

Citizen members are appointed by the Governor, and may serve up to two terms and a maximum of six years. Citizen appointments are staggered so one-third will expire each October. Agency representatives are appointed by their Secretaries or Commissioners, and DD network members by their directors, with one-year terms from October through September. The Council Membership Committee is responsible for member recruitment. In September the committee develops a recruitment plan for vacancies occurring the following year. The committee targets specific categories such as age, racial and ethnic diversity, geographical diversity, etc. The committee conducts individual candidate interviews and submits recommendations to the Council in March. Those approved by the Council are forwarded to the Governor's Office for appointment in October. If the Council fails to endorse enough candidates to fill all vacancies, the Membership Committee selects new candidates for a Council vote in June.

(ii) Council Members:

#	Name	Code	Organization	Appointed	Term Date	Alt/Proxy State Rep Name
1	Cazeau-Class, Sabrina	A1	MA Rehabilitation Commission	2013-Oct-01	2014-Sep-30	
2	Narvaez, Marie	A2	Department of Elementary and Secondary Education	2013-Oct-01	2014-Sep-30	
3	Mancusi, Charlene	A3	Executive Office of Elder Affairs	2013-Oct-01	2014-Sep-30	
4	Miller, Cynthia	A4	Executive Office of Health and Human Services	2013-Oct-01	2014-Sep-30	Edes, Rosalie
5	Griffin, Christine	A5	Disability Law Center	2013-Oct-01	2014-Sep-30	Kane, Veronica
6	Kiernan, William	A6	Institute for Community Inclusion	2013-Oct-01	2014-Sep-30	Helm, David
7	Gleason, James	A6	Shriver Center	2013-Oct-01	2014-Sep-30	Hamad, Charles
8	Hebert Carden, Crystal	A7		2012-Oct-01	2015-Sep-30	
9	Nordahl, Erik	A7	Attorney	2012-Oct-01	2015-Sep-30	
10	Osborne, Sandra	A7	Social Psychologist	2011-Oct-01	2016-Sep-30	
11	Gottlieb, Suzanne	A8	Department of Public Health	2013-Oct-01	2014-Sep-30	
12	Grossman, Gail	A9	Department of Developmental Services - Ex Officio	2013-Oct-01	2014-Sep-30	Hernandez, Victor
13	Goldberg, Naomi	A9	MA Office on Disability - Ex Officio	2013-Oct-01	2014-Sep-30	Berloff, Myra
14	Brown, Bethany	A9	Office of the Attorney General - Ex Officio	2013-Oct-01	2014-Sep-30	
15	Bartlett, Kate	B1		2011-Oct-01	2014-Sep-30	
16	Bevins, Briana	B1		2012-Oct-01	2016-Sep-30	
17	Conley, William	B1		2012-Oct-01	2015-Sep-30	
18	Grace, Catherine	B1		2008-Oct-01	2014-Sep-30	
19	Kunzier, Tim	B1		2010-Oct-01	2016-Sep-30	
20	Pierce, Debbie	B1		2008-Oct-01	2014-Sep-30	
21	Ryan, Kate	B1		2011-Oct-01	2014-Sep-30	
22	Sandberg, Daniel	B1		2011-Oct-01	2014-Sep-30	
23	Brugnaro, Lora	B1	Vice-Chairperson	2006-Oct-01	2013-Sep-30	
24	Ching, Lisa	B2		2007-Oct-01	2013-Sep-30	
25	Milorin, Henry	B2		2011-Oct-01	2016-Sep-30	
26	Sacks, Irving	B2		2008-Oct-01	2014-Sep-30	
27	Smith, Robert	B2		2007-Oct-01	2013-Sep-30	
28	vanBruinswaardt, Caroline	B2		2009-Oct-01	2015-Sep-30	
29	Fitzpatrick, Julie	B2	Chairperson	2010-Oct-01	2016-Sep-30	
30	Glennon, Dianne	B3		2007-Oct-01	2013-Sep-30	
31	Washington, Donald	C1		2011-Oct-01	2016-Sep-30	

PART E: Council Staff [Section 125(c)(8)(B)].

#	Name	Position or Working Title	FT/PT %
1	Behum, Faith	Public Policy Specialist	100.00%
2	Britton, Kristin	Assistant Director - Policy and Programs	100.00%
3	DelTrecco, Adelia	Member Services Coordinator	100.00%
4	Fancher, Elizabeth	Grants Program Specialist	80.00%
5	Hall, Craig C.	Assistant Director - Finance and Operations	90.00%
6	Houghton, Sandy	Leadership Trainer/Self-Advocate Liason	80.00%
7	Huntley, Tamara	Leadership Trainer	40.00%
8	Jackson, Cathy	HR Manager / Communications Coordinator	100.00%
9	Larriu, Lee	Training Coordinator	100.00%
10	Lieberman, Harold	Assistant to the Budget/Admin Manager	80.00%
11	McAnespie, Ashley	Policy Specialist	80.00%
12	McLeod, Chezerae	Self-Advocacy Trainer/Supporter	40.00%
13	Mitton, Kimberly	Self-Advocacy Trainer/Supporter	40.00%
14	Shannon, Daniel	Executive Director	90.00%
15	Vacant	Budget and Administrative Services Manager	80.00%

16	Williams, Andre	Leadership Trainer	40.00%
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Section II : Designated State Agency

PART A: The designated state agency is:
The Council itself.

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

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

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

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

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 comprehensive review was conducted utilizing a variety of resources, including published and unpublished reports, national and state statistical data, partner and stakeholder meetings, and public surveys and comment. Council staff were primarily responsible for researching reports and data, and summarizing this information for the Council's State Plan Committee. Information was collected from the US Census, the American Community Survey, the State of the State in Developmental Disabilities, Status and Trends on Residential Services for People with DD, Institute for Community Inclusion State Data reports, state agency annual reports, non-profit research and reports, advocacy organization reports and numerous other federal and state sources.

Staff held meetings with partners and grantees to review the status of services and supports, as well as current Council initiatives, to solicit input for potential objectives. The Council also partnered with MA Advocates Standing Strong, the statewide self-advocacy organization, Arc Massachusetts, MA Families Organizing for Change and our DD network partners to solicit input from people with developmental disabilities and families. Meetings were also held directly with groups of self-advocates facilitating their completion the Council's State Plan Priority Survey.

The State Plan Committee consisted of seven Council members and was responsible for reviewing reports and data, reviewing state plan requirements, the Council's mission and current Council activities, and identifying the key potential areas for Council deliberation. The committee met with state policy officials from the Executive Office for Health and Human Services, the Department of Developmental Services and other state agencies responsible for overseeing services and supports to people with developmental disabilities and families.

The committee established a list of potential areas identified through their work and developed a State Plan Priority Survey. In addition to distributing the survey at various advocacy meetings, the survey was distributed through e-mail and posted on-line, and facilitation was conducted directly in meetings with self-advocates. The survey requested demographic information about the people responding, and respondents were asked to choose up to five of eleven priorities for Council consideration. The eleven areas included Supporting Children, Supporting Families, Supporting Self-Advocates, Individual Rights, Community Living Opportunities, Independent Living Opportunities, Career Opportunities, Individual and Family Choice and Control, Emerging Service Needs, Community Engagement and Service Quality. Each category identified specific examples of potential goal areas.

The Council received 434 responses to the survey. The demographics of respondents were very consistent with the geography, age, race and ethnicity of the state population. 24% of respondents were people with developmental disabilities, a significant increase in respondents from previous Council surveys. The State

Plan committee utilized the priority results from the survey along with the information gathered through research and interviews to develop a priority list of potential goals and objectives. It presented its work and findings to the full Council for deliberation, from which the Council established a set of prioritized goals and objectives.

PART A: State Information

(i) Racial and Ethnic Diversity of the State Population:

Race/Ethnicity	Percentage of Population
White alone	82.4%
Black or African American alone	6.3%
American Indian and Alaska Native alone	0.01%
Asian alone	5%
Native Hawaiian and Other Pacific Islander alone	0%
Hispanic or Latino of any race	8.8%
Some other race alone	3.8%
Two or more races:	2.3%

(ii) Poverty Rate: **10.1%**

(iii) State Disability Characteristics:

a) Prevalence of Developmental Disabilities in the State: **153120**

This number is based on 2.32% of the total population, calculated by utilizing the increase in DD diagnosis rates over the past 10 years and adjusting up the Gollay rate of 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)
2011	208	175.000	33.000	158.230	46.700
2009	194	160.000	34.000	225.000	32.000
2007	196	150.000	46.000	216.000	23.000
2005	190	141.000	49.000	220.000	19.000

c) Demographic Information about People with Disabilities:

People in the State with a Disability	Percentage
Population 5 to 17 years	5.9%
Population 18 to 64 years	8.9%
Population 65 years and over	34%

Race and Hispanic or Latino Origin of People with a Disability	Percentage
White alone	11.2%
Black or African American alone	13.3%
American Indian and Alaska Native alone	17.8%
Asian alone	5.5%
Native Hawaiian and Other Pacific Islander alone	0%
Some other race alone	15.3%

Two or more races	12.7%
White alone, not Hispanic or Latino	11.1%
Hispanic or Latino (of any race)	13.6%

Employment Status Population Age 16 and Over	Percentage with a Disability	Percentage without a Disability
Employed	22.8%	69.1%
Not in Labor Force	72.1%	24.4%

Education Attainment Population Age 25 and Over	Percentage with a Disability	Percentage without a Disability
Less than High School graduate	25.5%	8.2%
High School graduate, GED, or alternative	36.3%	24.3%
Some college or associate's degree	21.5%	25.1%
Bachelor's degree or higher	16.7%	42.4%

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	32%	19.1%
\$ 5,000 to \$ 14,999	9.8%	6.4%
\$ 15,000 to \$ 24,999	13.5%	11.8%
\$ 25,000 to \$ 34,999	11.1%	11.9%

Poverty Status Population Age 16 and Over	Percentage with a Disability	Percentage without a Disability
Below 100 percent of the poverty level	20.8%	7.9%
100 to 149 percent of the poverty level	13.3%	4.9%
At or above 150 percent of the poverty level	65.9%	87.3%

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

(i) Health/Healthcare:

The 2010 Annual Disabilities Statistics Compendium reported that in 2009 MA had the smallest number of uninsured individuals with disabilities. Only 4.2% lack coverage. 95.8% of Adults with disabilities have health insurance, higher than those without a disability (93.9%). In 2009, 62.7% of people with disabilities age 18 to 64 living in the community were covered by public health insurance; 46.3% were covered by private health insurance. The percent of total Medicaid beneficiaries with disabilities increased 2.0% between 2005 and 2007. In 2007 Medicaid payments for those with “disabled” status was 42.5% of total Medicaid payments. In 2008 the number of Medicare enrollees entitled by disability was 173,822, 17.1% of the total enrolled, an increase 0.1% from 2007. As one of the twelve wealthiest states in per-capita personal income MA receives the minimum Federal Medical Assistance Percentage (FMAP).

In 2011 MassHealth implemented benefit changes impacting dental coverage. However adults with ID/DD enrolled in MassHealth through the Department of Developmental Services (DDS) had no change in coverage. The DDS Medically Complex Program serves families with children and adults up to age 25 with special cognitive and physical healthcare needs, helping to avoid pediatric nursing home placement. The program serves 300 families each year as a supplement to MassHealth, assisting families to access supports not covered by health insurance. The DDS Autism Division oversees the Autism Waiver Program, to provide intensive supports for up to 110 young children with autism. Over 120 enrolled in the program in 2010 with a service package of up to \$25,000.

In 2010 MA passed an Autism Insurance law prohibiting private insurers from citing Autism as a previously existing condition to deny coverage, and requiring private health insurance plans to provide coverage of

evidence-based, medically necessary therapies for people with Autism of all ages.

The MA Department of Mental Health serves approximately 24,000 individuals, including 3,500 children and adolescents, with severe and persistent mental illness, primarily through case management. The FY11 Children's Behavioral Health Initiative (CBHI) funds improvements to MassHealth behavioral health services for recipients age 21 and under. The program focuses on early identification and intervention, requiring the use of a standardized behavioral health screening tool.

Home care assistance programs available for people with disabilities include the HCBS Waiver program that helps people with DD/ID and young children with Autism live safely in their communities, preventing institutionalization. The Kaileigh Mulligan program serves children with severe disabilities who need skilled nursing care or are dependent on assistive technology. The Personal Care Attendant Program under MassHealth assists people with long-term disabilities to live at home, providing funding to hire a PCA to help with activities of daily living.

The Barrier Free Health Care Initiative was initiated by Brigham and Women's and MA General Hospitals in 2009. It provides ongoing assessment of the hospitals' efforts to address the needs of people with disabilities. Improvements identified in the collaborative 6yr plan include removing architectural barriers, purchasing additional accessible medical equipment, and modifying hospital policies to improve care to people with disabilities.

Disparities and inequalities in healthcare faced by adults with ID/DD were reported by the Arc of MA in a 2008. The report concluded that healthcare professionals do not possess the required knowledge and communication skills to care for individuals with ID/DD, and quality and access to healthcare for people with ID/DD is lacking, partially due to a lack of knowledge of the healthcare system. The report identifies the need for formal care coordination to network between people with disabilities and healthcare professionals.

(ii) Employment:

The number of people served in integrated employment has risen gradually and steadily since 1990. The integrated employment rate in MA for 2009 for state ID/DD agencies was 52.61%. In 1996, funding was \$20,400,000. Integrated employment funding for MA state ID/DD agencies was \$38,178,399 in 2009, down \$7,971,092 from 2008. Supported employment is funded by state vocational rehabilitation services and the HCBS Waiver. In 2009, there were 3,469 participants in MA ID/DD agency- employment programs. 22% were in supported employment. Based on the provided funding, 78% of the applicants were not able to gain supported employment, and the Council is working to increase the number of individuals within supported employment.

The MA Rehabilitation Commission (MRC) and the MA Commission for the Blind (MCB) provide vocational rehabilitation services for the state. MRC's goals are to support competitive employment opportunities through vocational counseling, evaluation/assessment, job coaching, training, technology services and assistance in job placement. The number of vocational rehabilitation closures with successful employment outcomes for FY 2009 in MA was 3,035, and the vocational rehabilitation rate for the same year for MA was 55.4, below the U.S. rate of 57.8. Most closures in 2008 (96.4%) resulted in integrated employment. In 2009, the most significant change was the number of applicants for vocational rehabilitation, which increased by 697, but the number of vocational rehabilitation closures with successful employment decreased to 3,035. The number of applicants is increasing each year, but there are fewer people being placed in successful employment due to staff layoffs and the current fiscal environment. In order for more services to be made available, it is important to create partnerships and work with various state agencies in order to address this significant issue that is and will continue to be of concern.

The One-Stop Career Centers work with the Department of Developmental Services (DDS) and MRC funded

employment service providers. There are approximately 100 Employment Services Providers in MA utilized by DDS for job placement of young adults. Workforce Investment Boards oversee One-Stop Career Centers and implement the Workforce Investment Act, funding employment services for individuals aged 14 to 21. Job placement agencies that offer career planning and training include the Advantage Employee Network for Berkshire County and the Charles River Employment Vocational Services. Best Buddies Jobs works to integrate individuals with ID/DD into the community through employment.

In 2009 DDS established a cross-stakeholder statewide planning team and work group to create a Strategic Plan for Employment to promote and support increased integrated employment opportunities. DDS adopted an Employment First Policy which “provides clear direction and strategic focus” for DDS in identifying ways to promote and support increased integrated employment opportunities. The MA Disability Employment Initiative prioritizes employment for people with disabilities. The plan was developed under a partnership among the MA Executive Office of Health and Human Services, the UMASS Medical School, and the Institute for Community Inclusion. The public and private sector works together to support employment opportunities for individuals with disabilities.

Federal work-incentive programs are utilized in MA for individuals with DD. A few offered through the Social Security Administration (SSA) include Trial Work Months, Impairment-Related Work Expense (IRWE), and Student Earned Income Exclusion. Ticket to Work is an incentive that maximizes the choice of the individual in finding employment. Plan for Achieving Self-Support (PASS) allows SSI beneficiaries over 15 years old to set aside funds towards a vocational goal and to have those funds be excluded from consideration during eligibility determination of benefits.

(iii) Informal and informal services and supports:

Massachusetts' Home and Community-Based (HCBS) Waiver services finance a number of services and supports for children and adults with developmental disabilities. The Children's Autism Spectrum disorder waiver provides supports to participants including but not exclusive to respite, behavioral supports and consultation, family training, and speech therapy. In 2010, this program was renewed for five years; the number of participants that will be served each year is 130.

The MA Adult Supports Program services include group or center based day supports, individual support and community habilitation, supported employment, family support navigation, and transportation. This Waiver program was renewed in 2010, and by year three 2,818 will receive services. The MA Community Living Waiver provides services such as individualized home supports that assist individuals with intellectual disabilities to live in the community. This waiver program was renewed in 2010, and in year one 1,623 individuals were served. The Massachusetts Adult Residential Waiver program provides similar services to the Community Living Waiver program and also offers residential habilitation, residential family training and residential peer support. In year one of the renewed waiver program 7,673 individuals were served. The number of people served for each of these Waiver programs is predicted to serve the same number of individuals through year five of each Waiver program. This will have a positive impact on the DD community.

Multiple outlets exist for families seeking support. Across the Commonwealth, seven Autism Support Centers provide parent support groups and information and referral services for families dealing with an Autism diagnosis. Family Ties of Massachusetts, in collaboration with Early Intervention, provides parent-to-parent support, information and referral services, and workshops to ensure that parents feel confident in caring for their children with a disability. Other organizations such as Massachusetts Families Organizing for Change, focus on advocating for the rights of individuals with disabilities and their families by “organizing families and individuals to use the power of our numbers to effect positive change.” Other resources include SPED Child and Teen, a website created by a mother of a child with Asperger's Syndrome, which contains extensive resources and information for individuals and parents, including contact information for local early intervention agencies and many support groups across Massachusetts.

Massachusetts has multiple programs dedicated to informing professionals about the needs of individuals with developmental and intellectual disabilities. The Massachusetts Office on Disability (MOD), in partnership with the Massachusetts Emergency Management Agency (MEMA), hosts meetings to bring together people with disabilities and local emergency preparedness professionals. These meetings explore how to ensure that people with disabilities have the assistance they need in times of emergency. The Autism and Law Enforcement Education Coalition or ALEC program educates police officers, firefighters, EMTs, paramedics and hospital emergency room personnel on how to interact with individuals with ASD in times of crisis.

Originally funded by the Council, Operation House Call (OHC) is a teaching program implemented through a partnership between the Boston University School of Medicine and the Arc of Massachusetts. Each third year medical student at B.U. attends a class taught by the OHC coordinator and then makes one visit, lasting about two hours, to a volunteer family that has a child with a developmental disability. The program is a requirement for medical students in their six week pediatric rotation.

(iv) Interagency Initiatives:

Massachusetts has many initiatives aimed at increasing collaboration among state agencies and non-state agency providers while improving services for individuals with developmental disabilities. The MA Interagency Coordinating Council (ICC) advises and assists in the planning, development and implementation of activities necessary to operate the statewide system of early intervention services. Six parent representatives from across the state with children received or are receiving early intervention services, sit on the Coordinating Council's Family Leadership Team. The Team's goal is to engage families across the early childhood system and form partnerships between the families, providers of EI services, and state agencies.

The Department of Elementary and Secondary Education (DESE) and Department of Developmental Services (DDS) work in partnership to prevent residential placement of children with DD under 18 with extensive care needs. Children are prioritized by DDS to participate in the program. Families receiving DESE/DDS services develop a Family Plan and budget, and receive long-term intensive levels of support and case management from a Family Support Specialist. Once accepted, services may continue through the child's 22nd birthday, and may include any of the support options available through Family Centers.

The Disabled Persons Protection Commission (DPPC) and State Police Detective Unit (SPDU) partnership provides a statewide mechanism to ensure effective and rapid response to criminal complaints of abuse and neglect against persons with disabilities. They coordinate the efforts of adult protective services, human services, state and local law enforcement and the Commonwealth's District Attorneys' Offices. The SPDU reviews all abuse reports to DPPC's 24 hour Hotline and refers any that constitute criminal activity to the applicable District Attorney's office.

The Massachusetts Rehabilitation Commission's (MRC) Statewide Employment Services initiative collaborates with other employment programs including the Disability Employment Partnership, Employee Assistance Programs, Flexible Finance Initiatives, and the Informed Choice Initiative. This collaboration strives to administer programs and provide supports to assist people with severe disabilities to obtain and retain meaningful community based employment.

The Governor's Commission on Intellectual Disability was re-established in 2008 to examine the quality and comprehensiveness of services designed to address the wide variety of needs of people with intellectual disabilities. The Commission is an independent citizen oversight body consisting of 11- 13 members appointed by the Governor to work with DDS to meet its mission to support people with intellectual disabilities.

The Department of Mental Health (DMH) Inpatient Study Commission assists the Executive Office of Health and Human Services (EOHHS) and DMH with recommendations that achieve balance, independence and

objectivity in serving people with mental illness. The commission holds statewide public hearings, evaluates the DMH inpatient system, determines an appropriate inpatient capacity for the Department, and recommends a plan of action to the Secretary of EOHHS.

The Autism Commission, staffed by the Council, was formed in 2010 and charged to make an investigation and study the range of services and supports necessary for individuals with Autism spectrum disorders to achieve their full potential across their lifespan. The Commission consists of 31 members appointed by the Governor, including parents of individuals with Autism, self-advocates, professional advocates, service providers, representatives from state agencies and state legislators. The Commission has four subcommittees dedicated to exploring specific issues facing this population. Each subcommittee also has additional community members consisting of parents of individuals with Autism and self-advocates.

(v) Quality Assurance:

Massachusetts has a system of procedures and safeguards to prevent abuse, neglect and exploitation and improve quality service provided to people with disabilities. The Department of Developmental Services (DDS) has a rigorous quality management system that emphasizes quality improvement. The DDS Office for Human Rights uses oversight and evaluation to monitor and improve the quality of services and supports on an individual, provider and system wide basis, providing identification, correction, follow-up and technical assistance in areas affecting the health, safety, human rights and quality of life of individuals that DDS supports. DDS supports self-determination for individuals and promotes it with providers. Service options include person-centered planning, circles of support and support brokers. The Governor's Commission on Intellectual Disabilities examines the quality and comprehensiveness of the Commonwealth's program of services designed to address the wide variety of needs of people with intellectual disabilities.

The Disabled Persons Protection Commission investigates abuse of adults with DD, and it ensures that appropriate protective services are put in place when it determines that individuals are at risk for abuse. It also trains service providers, law enforcement personnel and the public in clarifying the presence of abuse and neglect. The Building Partnerships initiative is a multidisciplinary team comprised of DPPC, district attorneys, State Police, and state agencies to provide protection, treatment and continuity of care for persons with disabilities who are victims of a crime, to increase awareness of crimes being committed against persons with disabilities, and to increase communication and cooperation between law enforcement, professionals and agencies providing services to people with disabilities. MA Advocates Standing Strong, the statewide advocacy organization for people with developmental disabilities, partners with DPPC to conduct Awareness and Action training on recognizing and reporting abuse for self-advocates across the state.

The Department of Public Health's (DPH) Early Intervention program uses a General Supervision quality assurance system to monitor and ensure compliance. DPH also maintains a registry of offenders in home health, homemaker, hospice or nursing facilities. The Mass. Interagency Coordinating Council advises and assists the Department of Public Health on E.I. The ICC is comprised of parents, professionals, providers and state agency representatives.

Over the last 20 years, disability advocates have unsuccessfully tried passing legislation to ban the use of painful aversive shock therapies. DDS has recently proposed a change in regulations that would eliminate level III aversive treatments prospectively for individuals with DD entering the service system. In addition, efforts are being made in the legislature to address this issue.

Over the last 5 years, state agencies have joined together on task forces to improve programs that benefit people with disabilities, including emergency preparedness, housing, transportation, employment, respite and "Olmstead". State agencies and nonprofit organizations provide training in leadership, self-advocacy and self-determination. The Council conducts Self-Advocacy Leadership Series (SALS) across the state to both adults and students in transition. MA Advocates Standing Strong conducts extensive self-advocacy, as do

many local self-advocacy groups and some providers. Independent living centers offer advocacy training and peer support groups. Easter Seals and Boston's ILC provide youth leadership and advocacy skills training to teens and young adults. Mass. Families Organizing for Change provides annual family leadership training for parents across the state, and the Federation for Children provides parent training in special education and advocacy.

(vi) Education/Early Intervention:

Early Intervention in Massachusetts provides children and families with individualized services in a natural environment such as their home or a daycare center. Services available include home visits, center-based individual visits, community child groups, EI-only child groups and parent groups. Children with certain diagnoses such as hearing loss, vision loss or Autism Spectrum Disorder are referred to providers who specialize in appropriate interventions for these individuals. Intervention is designed to include the child, staff member(s) and parents. If family circumstances preclude parent participation, alternative strategies for communication with the parent are developed.

The MA Department of Public Health (DPH) has raised the certification standard for Early Intervention Specialists. Part of this certification requires a degree from an institution of higher learning in Early Intervention. To be considered fully certified, a minimum of 1,440 hours of supervised experience in a DPH-certified Early Intervention program must be met. Individuals needing training in order to become certified or those looking for professional development opportunities can access the Massachusetts Early Intervention Training Center online. This resource offers both online and in-person trainings and workshops for Early Intervention professionals.

The Massachusetts Department of Elementary and Secondary Education (DESE) is responsible for ensuring an appropriate education to all students living in the Commonwealth. DESE offers alternative learning options through private special education schools. There are 122 approved private special education schools certified by DESE in Massachusetts. Some programs focus on providing education for individuals with specific disabilities, such as the Boston Higashi School, a program specializing in individuals with Autism. Other programs offer residential services, vocational education, or education services to individuals with a wide range of developmental and intellectual disabilities.

Both public and private schools are mandated to complete the Chapter 688 Referral process two years before a student leaves special education or reaches 22 years of age. Parents must provide permission for the school to contact adult disability service agencies. The two year planning period allows time to determine eligibility for adult services and for adult service agencies to determine the anticipated cost of services for the student in budget requests. Chapter 688 referrals and supporting documentation are sent directly to the appropriate lead agency and to the Bureau of Transitional Planning (BTP) at the Executive Office of Health and Human Services.

The Office of Elementary School Services provides support through grant programs, technical assistance, professional development, evaluation, and policies to promote standards-based curriculum and authentic assessment that are integrated and aligned. Examples of grants programs include the Quality Full-day Kindergarten grant, a project to "support and improve inclusion of children with disabilities in the regular classroom and support the education of English language learners."

Other transition programs include the Inclusive Concurrent Enrollment Program (ICE), a state funded grant program that enables students with developmental disabilities to experience college while attending high school. Despite funding cuts the past two years the number of colleges participating in ICE has grown. The Arc of Massachusetts was awarded a grant through the Wal-Mart Foundation's School-to-Community Transition program. This program creates partnerships with local public schools and staff to increase transition outcomes and build inclusion and the involvement of youth with intellectual and developmental

disabilities in independent living, employment, post-secondary education, vocational training and community, social and civic affairs.

(vii) Housing:

The affordable housing crisis continues to present a formidable challenge to people with developmental disabilities and family members seeking affordable, accessible and integrated housing in Massachusetts. Metropolitan Boston ranks #5 among the most expensive housing markets in the country, where rents are at an all-time high and vacancy rates are at record lows. Theoretically, people with disabilities seeking housing have several options, including public housing, private subsidized housing, supportive housing, and vouchers for market rate housing. However, it can take months or years to obtain suitable housing. Also, Massachusetts risks losing thousands of subsidized rental units (9500 by 2019) due to “expiring use” contracts, which were initiated 40 years ago as incentives to develop affordable housing. Complicated building codes and housing discrimination also present significant barriers to housing for people with developmental disabilities.

Housing voucher programs in Massachusetts include federal Section 8 vouchers, the Alternative Housing Voucher Program (AHVP), vouchers for individuals with disabilities under 60 years old who are eligible for Chapter 667 Housing. AHVP currently serves 411 individuals. The Mass. Rental Voucher Program (MRVP) provides tenant and project based vouchers for low income families, many of which include household members with disabilities. AHVP and MRVP are currently frozen due to budget constraints. No new vouchers are being issued. Most of the local housing authorities that administer these programs have long waiting lists.

The Department of Developmental Services (DDS) provides different types of homes in the community for adults, including apartments, condos, small family settings and group living situations. Some homes provide 24 hour care, supervision, and training in basic life and community living skills. The homes are operated directly by DDS or by provider agencies under contracts with the Department. Most homes are single family residences with 4 or 5 bedrooms or side by side 4 bedroom duplexes. The demand for residential services far exceeds the supply.

The MA Rehabilitation Commission’s (MRC) Adult Supported Living Program enables adults with a physical disabilities and secondary disabilities to begin or continue living independently in the community with case coordination. The state’s 11 ILCs and other nonprofit agencies provide information and assistance to individuals seeking housing, including skills training to support independent living. Nonprofit housing and human service agencies also provide information and assistance to individuals. Some organizations offer fee for service individualized consultation to create specialized housing strategies, such as adult foster care, roommates and cooperative housing.

The Mass. Home Modification Loan Program (HMLP) provides loans of up to \$30,000 to homeowners who need to modify their homes with accessible features so that they can remain at home. Depending on income, homeowners can obtain a 0% deferred loan to be repaid when the house is sold, or a 3% amortized loan. Landlords of small rental properties can also use this program to modify units for tenants with disabilities. Easter Seals also provides home modification loans through its Mass. Assistive Technology Loan program. Massachusetts offers several affordable housing development programs, including no interest loans to develop housing for DDS clients and community based housing for residents with disabilities who are not in the DDS or DMH system. Approximately 1500 affordable units are developed each year.

MassAccess is an online accessible housing registry administered by The Citizens’ Housing and Planning Association (CHAPA). Users can search for subsidized and market rate rental housing by location, size, availability and accessibility. Affordable housing units for sale are also listed.

(viii) Transportation:

Most public transportation infrastructure is concentrated in and around metropolitan Boston. In other areas of the state, 15 Regional Transit Authorities (RTAs) serve 231 cities and towns, primarily with bus and trolley service in densely populated areas. There are significant transportation gaps in less populated and rural areas. Public transportation is often limited in its routes, days and frequency of operation. Some communities, along with their RTAs, have developed local coordinated transportation plans that offer unique programs for residents, addressing local transportation challenges.

In greater Boston, the Mass. Bay Transportation Authority serves 175 communities and 1.2 million riders daily. It operates a subway system in the greater Boston area along with accessible bus, commuter rail and ferry service. It offers reduced fares and monthly passes for passengers with disabilities, and free passage to blind passengers. All MBTA buses are required to be accessible. Service animals are welcome on all MBTA property. Due to an aging infrastructure, many subway stations and older trains are inaccessible to people with mobility impairments. Since 2006, when a multi-million dollar settlement to improve the MBTA's accessibility was reached, access has improved significantly. Elevators, escalators, bridge plates for gaps between platforms and trains, portable lifts, mini-high platforms, tactile warning strips at platform edges, and emergency evacuation chairs are some of the access features that now exist in MBTA stations. Customers can receive instant alerts about elevators and escalators that are out of service, and MBTA drivers are trained in customer service and transporting people with disabilities.

The Regional Transit Authorities operate Para-transit services, providing transportation within ¾ mile of fixed bus and train routes. Para-transit services operate on the same schedules as public transit, so off-peak and weekend travel is limited. Passengers must reserve a ride a day or more in advance. The RIDE in Greater Boston uses lift-equipped vans and operates daily in 62 cities and towns. On July 1, 2012, passenger fares were raised from \$2.00 to \$4.00. Personal Care Attendants still ride free of charge. This fare increase will have a significant financial impact on the DD community and is part of a much larger cost issue throughout the Commonwealth's transportation system.

Established in 2001, the Human Services Transportation (HST) Office works to support and increase transportation options for eligible individuals with disabilities to access health care, jobs, and community-based supports. HST manages a large brokered transportation system for over 37,000 individuals. Some RTAs implement transportation requests and subcontract with local transportation vendors to provide over 5 million trips each year. HST provider agencies determine eligibility, transport locations and service areas. They ensure adequate funding of approved services and reimburse the brokers for trip costs. HST manages transportation for 5 human service agencies: MassHealth - Non-emergency medical transportation; Department of Developmental Services - transportation for adults enrolled in day habilitation, day service, supported employment and residential support programs; Department of Public Health Early Intervention Program - transportation to and from EI programs for children (0 to 3 years) and families; MA Rehabilitation Commission - transportation to vocational rehabilitation services, community services and other authorized locations or programs; and MA Commission for the Blind - transportation for blind individuals to social and rehabilitative programs and services, and other authorized locations or programs.

(ix) Child Care:

There are 22 Intensive Flexible Family Support Programs (IFFS) in the state that serve about 450 children ages 3-18 each year. IFFS funding was \$2 million for FY 2011. These programs have a large impact on the DD community because the program provides services and resources to support families in times of family crisis, and flexible funding to purchase additional supports or goods. DDS also offers other services such as the Medically Fragile Family Partnership, as well as supports various Specialty Family Support Services, including the Family Leadership Series, Autism Support Centers, after school programs, planned facility-based respite, and camp programs.

Planned Facility-Based Respite consists of an out-of-home respite service for children that provides short-term temporary relief to families caring for them at home. It includes overnight, weekend and/or vacation stays, and a variety of recreational, social, cultural and/or educational activities. There are two programs in Massachusetts, one located in the Metro Boston Region and one in the Central/West region. Between FY2009 and FY2010, this program lost 40% of its funding and was only able to serve 115 children and stopped serving adults. In FY2011, they were able to serve 120 children, with total funding for this service at \$385,000. This has had a significant impact on the community because of the larger burden now placed on the families. The Council is working to increase funding for this program, as well as the number of people served by this program.

DDS offers family support services for families who have a child with a disability. The budget reductions in FY 2010 and FY 2012 have brought about significant changes in the Family Support Services system. Family Support services are funded through the Family Appropriation Account in the state budget, which in FY 2010 was \$46,521,184. With these significant changes, the FY 2011 budget decreased by about \$1.5 million to \$45,004,298, and was \$41,004,298 for FY 2012. This has had a significant impact on the families because DDS has had to significantly decrease the supports and programs available. DDS has created newly funded Family Support Centers to replace the previous family support programs and are expected to act as a “hub” for an array of family support services, including childcare. Centers are expected to offer six family-relevant trainings per year, to collaborate with other providers and organizations, and to facilitate networking. About 6.8 million dollars fund the 33 Centers in MA in 2011.

(x) Recreation:

The Department of Conservation and Recreation's (DCR) Universal Access Program provides outdoor recreation opportunities in Massachusetts State Parks for visitors of all abilities. Accessibility to State Parks is achieved through site improvements, specialized adaptive recreation equipment, and accessible recreation programs. All 20 State Parks' swimming pools are equipped with swimming pool lifts and are free of charge. DCR also partners with All Out Adventures, a non-profit originally formed with funding from the Council, to offer accessible outdoor recreational activities.

Some options exist for locating recreational activities and researching activity accessibility for individuals with developmental disabilities living in Massachusetts. Bostnet Guide to Boston's Before & After-School Programs has developed a network of out-of-school-time resources and opportunities available to children with and without disabilities. The Council's 2010 Gopen Fellow established a web site, Explore Boston, to provide information on Boston attractions that are accessible, child-friendly and close to public transportation.

There are many organizations providing recreational opportunities in Massachusetts for individuals with developmental disabilities. Boston Families for Autism provides programs and activities such as social/sensory gyms and social/swim programs for individuals on the Autism Spectrum. AccesSport America inspires higher function and fitness for children and adults of all disabilities through high-challenge sports and training. CAPEable Adventures offers sports rehabilitation programs to anyone with a permanent disability. The Cape Cod Challenger Club Family Circle Sunday Respite Program provides swimming and music therapy for individuals with neurological impairments. Kids in Disability Sports (K.I.D.S.) hosts dances, sports banquets, social activities and recreational events throughout the year, serving individuals and families throughout Eastern Massachusetts. Participants range in age from 5-40 and have varying disabilities.

Best Buddies pairs individuals with developmental disabilities with volunteers to establish one-to-one friendships. E-Buddies pairs individuals with intellectual disabilities with peer volunteers in a pen-pal relationship via e-mail. The House of Possibilities (HOPE) offers opportunities to engage in social and recreational activities to adults and children with developmental disabilities. Partners for Youth with

Disabilities provide mentoring programs that assist young people reach their full potential.

The Massachusetts Down Syndrome Congress offers networking opportunities and a program called Advocates in Motion (AIM) which provides inclusive and interactive events each month for young people with Down syndrome between the ages of 13 and 22.” Search Beyond Adventures offers supervised, assisted tours, including monthly trips to Orlando and L.A., to adults with developmental disabilities. The Easter Seals Camp and Recreation Programs provide residential and day camps, all-inclusive recreation and sports camps, and respite services. Exceptional Vacations LLC offers all-inclusive vacation packages for adults with disabilities.

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

(i) Criteria for eligibility for services:

State agencies use strict eligibility criteria to determine if individuals can receive specialized services and supports. Much of these criteria are based on federal regulations, e.g., IDEA and Medicaid. Criteria that can exclude people with developmental disabilities from receiving services include age, income, type of disability, severity of disability and limited enrollment periods. People seeking state assistance must qualify for services based on the eligibility criteria of each individual agency. While many individuals meet the minimum eligibility criteria, it does not assure that the individual will receive services. Ultimately it is agency funding and capacity that determines if individuals will receive services. Ineligibility is not the predominant factor excluding people with DD from receiving appropriate services and supports. Available state resources are insufficient to support the needs of all eligible residents.

Eligibility for services is frequently determined by age. Early intervention covers infants and children ages 0-3; special education covers ages 3 to 21 years old; “Turning 22” is for youth transitioning to adulthood; vocational rehabilitation covers adults seeking employment and independent living services; and the Family Caregiver Support Program covers individuals or caregivers of adult children with DD who are older than 60.

Deep budget cuts have prompted state agencies to restrict eligibility criteria. The Department of Developmental Services (DDS) supports adults who have intellectual and related disabilities to live and work in the community, and families of children with DD under age 18. Individuals seeking DDS services and supports must have an intellectual or related disability, be enrolled in MassHealth, be eligible for ICF/MR admission and want to live in the community. Other criteria are determined by whether an individual's services are funded through the Adult Supports Waiver, Community Living Waiver, or Adult Residential Waiver. Available funding ultimately determines the number of people receiving services. Of the total estimated DD population of 153,000, DDS provides services and supports to approximately 32,000 adults and 8,600 children. Individuals with high functioning Autism, Asperger's Syndrome and others requiring minimal supports are rarely eligible for DDS services.

Under the revised Early Intervention criteria, a child must now exhibit a 30% level of delay or 1.5% standard deviation in one developmental area. Young children not meeting these deficits who have Autistic symptoms require a specific diagnosis for EI services, but it can take months to see qualified Autism specialists. Family co-pays have steadily risen; prior to 2003, no co-pays for EI were required.

Eligibility for special education services is based on IDEA regulations. There are widespread reports of school districts denying appropriate education services to students with developmental disabilities. During FY10, the Bureau of Special Education Appeals received 7,875 rejected Individual Education Plans (IEPs). Not all of these were for children with DD, nor were all unsatisfactory IEPs appealed.

Programs created for specialized populations exclude individuals who need similar supports. The MA

Rehabilitation Commission's (MRC) Acquired Brain Injury waiver provides funding for people who acquire brain injury after age 22, so in most cases people with DD are excluded. DDS' autism waiver provides intensive services to 130 children with severe autism under 9 years of age. Since 2007, there have only been 2 limited application periods of 10 days each.

Mass. Rental Vouchers are restricted to households earning less than 200% of the Federal Poverty Level, excluding residents with higher incomes who need accessible housing. The Alternative Housing Voucher Program is exclusively for people with disabilities under age 60 eligible for Chapter 667 housing.

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

Some data for this report was derived from the National Core Indicators (NCI) State Report for Massachusetts from 2008-2009. The percentage of males with a developmental disability who participated in the NCI data collection who were receiving services was 58.7% while 41.3% of females were receiving services. The MA percentage of males receiving services was 3.2% higher than the national average while the percentage of women receiving services was 3% below the average. The 2009 US census data indicates that 47% of people with a disability in Massachusetts were male and 53% were female. Despite women outnumbering men, the NCI data indicates that more men are receiving services. It is difficult to determine whether this reflects women not requiring as many services as men or that women are not receiving the level of services they require.

Individuals with Autism are significantly under-served in Massachusetts. According to a report produced by Advocates for Autism of Massachusetts (AFAM), between 2003 and 2009 the number of students diagnosed with Autism in Massachusetts doubled. Due to eligibility requirements for services based on having an IQ of 70 or less, the Department of Developmental Services does not serve thousands of individuals with Autism who are in need of support. The Department of Mental Health also does not offer services to individuals with Autism, as they determine most ineligible due to their Autism diagnosis.

A survey produced and disseminated by AFAM found that 76% of the 262 respondents with Autism and an intellectual disability diagnosis were turning 22 and graduating high school in the near future. More than half of these individuals (68%) indicated that they lived at home with their families and needed assistance with daily living skills. As these young men and women mature out of the special education system, the Massachusetts's Department of Developmental Services is faced with meeting their needs in an environment where funds are not sufficient to meet the demand for services. It is important to note that the AFAM report only portrayed the population of individuals eligible for DDS services. There are thousands more living with Autism who are not eligible for most state services and are in desperate need of assistance as they transition to adulthood.

The American Community Survey of 2009 indicates 627,654 individuals who identified as Hispanic are living in MA, and that 47,043 (4.5%) of these individuals had a cognitive disability. Research indicates a person with a developmental disability's race can ultimately predict the type of health care he or she will receive. Parish et. al. found that Latino children with Autism and other developmental disabilities were less likely than White children to have a usual source of care, had more difficulty getting referrals for services, and were more likely to experience cultural insensitivity from medical providers. Although this research was not specific to Massachusetts, it supports the contention that that many non-white individuals with developmental disabilities struggle with language and cultural barriers to medical care and other services in the state.

(iii) The availability of assistive technology:

There are many programs in MA providing assistive technology to people with disabilities. The Assistive Technology Program was created in 1999 to enable individuals with severe disabilities to access devices and training. Those with vocational or work goals are provided services through the MA Rehabilitation Commission (MRC). Individuals with disabilities who are eligible to receive services from other agencies are referred to those agencies for assistive technology services. School age children with disabilities eligible for Chapter 766 services must apply through the Local Education Agency for school related assistive technology equipment needs. Assistive technology regional centers offer people with disabilities the opportunity to trial devices for up to four weeks free of charge. 932 devices were loaned in 2010. The regional centers also invite individuals with disabilities, family members, educators, and service providers to product demonstrations.

MassMATCH is funded by the U.S. Department of Education under the Assistive Technology Act of 1998, and is one of 56 state-level assistive technology initiatives in the United States. Through partnerships with community-based organizations, MassMATCH is currently creating new assistive technology programs and working to coordinate services throughout the Commonwealth. MassMATCH provides information on various loan programs funded by public and private sources that are available for purchasing assistive technology, durable medical equipment, home modifications, vehicles and vehicle modifications. MassMATCH also provides listings to connect individuals to assistive technology vendors.

The program includes the MA AT Loan Program, a state funded initiative that gives people with disabilities and their families access to low interest loans to purchase assistive technology. In 2011, the AT Loan Program loaned \$1,245,580 to 72 borrowers, with 75% approval rate, keeping the same level with the national approval rate. 56% of the approved loans were made to applicants with income above \$35,000 per year. 22% went to incomes of \$15,000 per year or less. The average loan was \$17,300. 54% of the approved loans were interest-buy down only and 46% were interest buy-down with a loan guarantee (extending credit to applicants who would not otherwise have been approved by the lender).

The Commonwealth operates the Home Modification Loan Program to provide low interest and no interest loans for people with disabilities who need safety modifications such as ramps to their permanent residence. Central Bank and Citizens Bank also offer various loan programs to assist people with disabilities and their families make home modifications.

Easter Seals of Massachusetts provides a variety of assistive technology programs and services for children and adults with developmental disabilities. The Assistive Technology Regional Center (ATRC) helps people with disabilities in Eastern Massachusetts make informed decisions about assistive technology they can use to increase their independence at home, on the job or in school. Individuals and groups can explore hundreds of high- and low-tech devices that can meet a variety of needs. They are also allowed to bring some of the devices home to test them out. This free program is funded by the Rehabilitation Service Administration (RSA) of the U.S. Department of Education under the Assistive Technology Act. The Perkins School for the Blind offers training, equipment demonstrations, technology assessments for education, evaluations of people with low vision and other disabilities, software testing, and consulting for making websites accessible. The Assistive Technology Exchange of New England serves as a classified resource that brings buyers and sellers of assistive technology together. There is no cost to post an item on the exchange. People will often post assistive technology items that are available at no cost.

(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	66.000	32044	485.500		0.000	0.000
2009	65.940	31065	471.110		0.000	0.000
2007	65.480	30747	469.560		0.000	0.000
2005	63.980	29787	465.510		0.000	0.000

b. Description of the State's wait-list definition, including the definitions for other wait lists in the chart above:
The State keeps no formal wait list data. The state began initiatives to eliminate the waiting lists in 1996. The state's responsibility to serve all eligible individuals in appropriate community settings was memorialized as part of the settlement agreements under Rolland vs. Cellucci (Nursing home - 1999) and Boulet vs. Romney (Waiting list - 2001). The state acknowledges that there are individuals with developmental disabilities being served who are waiting for more appropriate services but does not consider that data to constitute an active waiting list. Efforts are being made to require the state to keep comprehensive waiting list data on individuals who are not receiving the level of services and supports identified in their needs assessments.

c. To the extent possible, provide information about how the State selects individuals to be on the wait list:
All individuals eligible for services are required to receive some level of support.

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

- ☐ Case management authorities
- ☐ Providers
- ☐ Counties
- ☒ 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):

- ☐ No services
- ☒ Only case management services
- ☒ Inadequate services
- ☒ Comprehensive services but are waiting for preferred options (e.g., persons in nursing facilities, institutions, or large group homes waiting for HCBS)
- ☐ Other: see description below

Other services:

Other services description(s):

Many individuals receive only minimal case management services.

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



Yes/No

Use space below to provide any information or data related to the response above:

All individuals go through an eligibility and needs assessment. This information is used to determine the level and type of services the individual requires and to prioritize the services and supports offered. Individuals receive information about options that are available or may be available in the future.

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):



Yes/No

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

Some individuals receive services or supports in inappropriate environments. According to statistics released by the Department of Developmental Services (DDS), in 2010 approximately 200 individuals were waiting to be transferred from nursing home to community settings and 160 students were eligible for but waiting to receive services under the DDS/Department of Elementary and Secondary Education program.

j. Summary of waiting list Issues and Challenges:

The requirement to serve all eligible individuals has created a tiered approach to services where those with the lowest priority receive only minimal case management services or and/small family support stipends. According to a 2010 survey conducted by Arc Massachusetts, there are 3,000 people awaiting family supports, 600 awaiting residential services and 360 individuals awaiting Day/Employment services. Efforts are being made to require the state to keep comprehensive waiting list data on individuals who are not receiving the level of services and supports identified in their needs assessments.

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

Funding for people with disabilities in Massachusetts has lagged behind the national average the last 6 years. From 2004 to 2006, the country as a whole grew 3 percent while Massachusetts fell 2.8 percent. Over the past two years, the drop-off has been precipitous. As of FY 2010 the Department of Developmental Services (DDS) budget was lower than FY 2001, when adjusted for inflation. The state has cut spending for disability services by nearly \$80 million over the past three years. Although programs serving people with developmental disabilities have fared better than other disability programs, and agencies have worked hard

to limit the impact of cuts, the level of cuts has still resulted in a reduction of available services and supports. More important, the state is falling further behind in supporting the growing level of need. Individuals with developmental disabilities entering the adult service system have limited options due to a lack of adequate resources.

Based on the Council's comprehensive analysis and data obtained from advocacy groups most programs are significantly under-funded. It is estimated that the FY 2012 budget under-funded Day/Employment and Family Services Programs by 7.2%, impacting approximately 1400 individuals and families. The DDS/DESE program line-item was once \$10 Million but has been under-funded for the past three years. Direct Support Professionals continue to earn far below a living wage and have had no salary increases for three consecutive years.

Over 600 students turn 22 each year thereby losing special education funding. Many adults continue to be supported by family and get little funding for work, day or in-home supports. Fewer than 200 get any type of residential help or housing; of those, 25-30% are wards of the state, at constant risk of ending up in a shelter. In addition, funding for essential Employment and Transportation services continues to decline due to more than a decade of inflation, and critical in-home supports for families have been lost due to budget cuts, escalating risks to families and costs for state.

Implementing the state's Community First Initiative has essentially been put on hold due to budget constraints. Effective implementation requires expansion to the DDS residential line items along with DDS employment/day and MassHealth day habilitation for clinical services. The day/employment and transportation accounts are utilized by adults who continue to live at home or transitioned through Community First. For those at home, these services are the main supports an adult receives from the state. It typically gives parents a break for the day or allows them to work. Funding in residential for Community First requires an additional \$32 Million above current funding, and it is estimated that a minimum of \$3 Million is necessary to effectively serve Turning 22 students.

In recent years most children have lost use of the Family Support/Respite services program due to cuts. For those with loved ones at home it is a cost-effective and essential support. In addition, staff at family support centers provide training, help with planning and give referrals for community resources that can complement public services. A reduction of more than one-third on top of past cuts means that families who have an adult son or daughter living at home or those with children who need assistance will have little if any help.

Adult Foster Care (AFC) is a growing alternative to residential programs. It allows adults to move in with other adults or families and share in their lives. It is the most cost effective residential option although it requires additional resources for individuals with higher needs for assistance. This program also has an option for families who have an adult family member living with them. The modest family stipend allows for respite, transportation and social activities. \$4 Million is needed to adequately fund this account.

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

In 2009 the Department of Developmental Services began implementation of the Community Services Expansion and Facilities Restructuring Plan to reconfigure the state facilities and to expand services available in the community system. The plan targets closing four of the six developmental and regional centers between FY 2010 and the end of FY 2013. The facilities targeted for closure include the Fernald, Templeton, and Monson Developmental Centers and the Glavin Regional Center. The Wrentham Developmental Center will remain open indefinitely to serve individuals in the closing facilities that choose to remain in an intermediate care facility. A decision on the future of the Hogan Regional Center has been deferred. As of June 2011, none of the facilities have been closed. Fernald, targeted first, has only 14 individuals remaining, all of whom have filed court action in an effort to remain at the facility.

Due to the level of court involvement over the past few decades the standard of services to individuals in facilities is consistently monitored and measured for quality. Based on the level of satisfaction among individuals and their guardians services are considered to be very good. This level of quality is often cited by facility advocates as a primary reason for maintaining institutional settings. It must be noted that this perceived level of quality is primarily based on an expectation of care as opposed to independence or inclusion.

Data shows that over 98% of DDS consumers surveyed through licensure and certification receive annual physical exams. The rate for individuals in facilities is 100%. Licensure and certification findings found that 97% of the individuals reviewed had had at least an annual dental exam. Concerning healthy lifestyles, NCI data for three New England states shows an inactivity rate of 21% for people with disabilities, compared to only 10% for the general population. Over the past five years almost all individuals reviewed during Survey and Certification reviews have been found to be receiving necessary support to promote a healthier lifestyle.

There have been improvements in the percentage of people with both annual physical (medical) exams and dental exams over time, and the disparity seen in earlier years between dental and medical exams has been substantially reduced. In FY 2008 there was only a 1% difference between physical exams and dental exams, compared to a 5% difference in FY 2004. This suggests that individuals in facilities are able to access basic dental and medical care at the same level as those in the community

Research in Massachusetts indicates that every month one out of every 10 nursing home residents suffers from a medication related injury. Within DDS programs, data indicates that about one out of every 1,400 people receiving medication experience a serious occurrence per month. Very few of those result in an actual injury. Almost 3 out of every 4 were due to a medication being administered at the wrong time (within an hour before or an hour after the scheduled time). Most of these "wrong time" occurrences were related to an omission (i.e., the medication was not administered).

(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))):

The Commonwealth has three new federal home and community based waivers, effective July 1, 2010. These waivers replace the previous home and community based waiver. Approximately 12,000 individuals are funded through these waivers, 7500 through Adult Residential, 2800 through Adult Support and 1700 through Community Living.

The Adult Residential Waiver has no cap and is utilized for individuals who need a residential placement that has supervision and staffing, 24 hours a day, seven days a week. It contains comprehensive service options including Residential Habilitation, Respite, Behavioral Supports and Consultation, Home Modifications and Adaptations, Individual Goods and Services, Occupational Therapy, Supported Employment, Day Habilitation Supplement, Transportation, Group or Center Based Day Services, Individualized Day Supports, Physical Therapy, Residential Family Training, Residential Peer Support, Self-Directed 24 Hour Supports, Speech Therapy, Stabilization and Transitional Assistance Services.

The Adult Supports Waiver has a \$28,000 cap and is utilized for individuals who can live in their own home or apartment or their family home. Service options include Individual Support and Community Habilitation, Supported Employment, Day Habilitation Supplement, Family Support Navigation, Individualized Day Supports, Transportation and Group or Center Based Day Supports.

The Community Living Waiver has a \$65,000 cap and is utilized for individuals who can live in their family homes or in the home of someone else or their own home and do not need supervision 24 hours a day and seven days a week. Services options include Homemaker, Individualized Home Supports, Supported Employment, Day Habilitation Supplement, Transportation, Group or Center Based Day Services,

Individualized Day Supports, Live-in Caregiver, Respite, Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Community Peer Support, Home Modifications and Adaptations, Individual Goods and Services, Occupational Therapy, Physical Therapy, Specialized Medical Equipment and Supplies, Speech Therapy, Stabilization, Transitional Assistance Services and Vehicle Modification.

The Children's Autism Home and Community-Based Services Waiver program provides services for Medicaid eligible children diagnosed with an autism spectrum disorder. The program serves children, birth through age 8, with an autism spectrum disorder who meet the limited eligibility criteria. The program helps children with autism remain in their homes and actively participate in their families and in their communities. The original model demonstration program, which ended on September 30, 2010, served approximately 110 children. The Renewal Waiver will serve an additional 60 children and contains a reserved capacity for children who are age 3 and transitioning out of an Early Intervention Program. 10 statewide slots are reserved for children who are age 3. These children may receive 3 years of the intensive in-home services. After that a child may access ongoing Supplemental Services to help with the transition out of the Early Intervention program until the child's 9th Birthday.

The waiver program provides one-to-one behavioral, social and communication based interventions, through Expanded Habilitation. The waiver program also provides related support services such as community integration activities and respite. The child must have a confirmed diagnosis of an Autism Spectrum Disorder, must be eligible for MassHealth Standard coverage, based on family income, not yet reached his/her 9th birthday, meet the level of care required for services in an Intermediate Care Facility for persons with Intellectual Disability (ICF/ID), and have a legally responsible representative able to direct the services and supports of the waiver. The family must choose to have the child receive services in the home and community.

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

The Council used four primary criteria to establish goals; the greatest areas of need, needs prioritized by the public, a clear and specific role for the Council and long term impact. The State Plan Committee compared input from state agencies and other organizations with the needs identified through research and data, and reviewed current and past activities to determine whether continuation is warranted. Recognizing that the Council cannot address all areas, public input was utilized to aid the Council in prioritizing goals. Council findings fall into four major priority categories; preparation for adulthood and jobs, quality of community living, leadership and self-direction. Consistent themes within each category include individual choice and control and building the capacity to serve people with Autism. Recognizing that these categories and themes overlap the Council has established seven goal areas for the State Plan: Transition, Leadership, Employment, Supporting Families, Homes, Community Supports and Self-Direction. Many goals and objectives for 2013 were re-written to better measure success as per the recommendation of the AIDD peer review team.

In TRANSITION, the Council will focus on skill building and leadership activities to prepare youth with DD for adulthood. Policy work in this area will focus on enhancing quality transition services, and efforts to better connect people with post-secondary opportunities. Under LEADERSHIP, the level of available supports and training does not exist to meet to the demand. The Council will take the lead in establishing a training consortium with partner organizations, combining efforts to expand training and other opportunities. The Council will also continue the eminently successful Gopen Fellowship.

In EMPLOYMENT the Council identified opportunities for competitive employment as the greatest need, and will undertake a new initiative to conduct training to assist individuals to build work portfolios. In addition, the Council will focus policy efforts on improving employment supports to individuals with Autism. A disturbing

trend that has resulted from budget cuts is a counter-intuitive reduction in family support. Family supports are the most cost-effective way to support those who are under-served, and an expansion would assist the state while it struggles to meet an ever expanding need. The Council will undertake initiatives in SUPPORTING FAMILIES to address this, including activities addressing family support to Asian families and education on respite resources.

Community living encompasses many aspects of life for people with DD. The Council's analysis concluded that the lack of affordable and accessible housing remains the major barrier to independence and will undertake initiatives under HOMES to educate families and expand the use of alternative housing options. The Council will actively support the Commonwealth's community expansion plan and the closure of state facilities, and undertake efforts to address community supports for people with Autism. Community living is also affected by the quality of services and supports received. Families and individuals stress that the support they receive from others is critical to their success. Under COMMUNITY SUPPORTS the Council will undertake efforts to increase the use of Positive Behavioral Supports. Policy activities will also be conducted to increase the capacity to protect the human rights and safety of people with DD.

In SELF-DIRECTION, the primary issue remains barriers to providing real opportunities for choice and control. Building on the work conducted by the Council supported Alliance for 21st Century Disability Policy the Council will undertake policy efforts to enhance self-direction for people with DD. The Council will also undertake an initiative to assist individuals with DD to acquire the skills needed for self-sufficiency through the establishment of Independence College.

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

(i) As a Network:

The DD Massachusetts DD Network developed its first network collaboration plan in 2006. The plan delineates the collaborative activities of the network, identifying specific goals and objectives, timelines for completion and lead agencies. The current plan includes the following goals:

- The capacity of the self advocacy movement in Massachusetts will continue to be increased. –DDC
- People with DD participate in leadership and self-advocacy training specific to reducing or eliminating abuse, neglect and exploitation. –P&A
- People with DD and their families are empowered to make choices about their needs through improved access to information & referral mechanisms. – Shriver UCEDD
- People with DD and their families identify and prioritize their unmet needs providing guidance to the DD Network. –P&A
- Individuals with DD and family members are involved in the development of an individual and family centered comprehensive service system. – ICI UCEDD
- Individuals with DD and their families are knowledgeable about their health care needs and the resources available to address them. –Shriver UCEDD
- Individuals with DD have opportunities to develop leadership skills. –DDC
- The DD Network is an active, communicative, and coordinated network.

The network will be developing an updated plan in the fall of 2013.

(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 developing goals and objective for the State Plan the Council has engaged with network partners both individually and as a group to identify areas of collaboration to be included in the Plan. With the ICI UCEDD we will continue the successful Gopen Fellowship. The fellowship fosters the leadership capability of an individual by supporting that individual's development of a project, to enhance their general understanding of how the system of disability services works both in the Commonwealth and on the federal level, and to build the capacity of the Fellow's personal leadership skills. The potential for expanding to a second fellowship, supported by the Shriver UCEDD and the P&A will be discussed in the fall.

The Council will continue its partnership with the P&A to support a cross-disability self-advocacy coalition. The purpose of the coalition is to develop and address joint policy, budget and legislative objectives that enhance inclusion and community living opportunities for people with developmental and other disabilities. In addition, the Council and P&A will work collaboratively on policy issues related to transition, and as partners on the MA21 Collaborative Group, working to enhance self-directed community-based supports and services for individuals with disabilities and family members.

(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 DD Network collaborates with other entities throughout the Commonwealth. In partnership with the Department of Developmental Services the network established the DD Funders Group to support the efforts of Massachusetts Advocates Standing Strong (MASS), the statewide self-advocacy organization for people with developmental disabilities. In addition to coordinating resources, the group meets with the MASS board on a quarterly basis to provide support to assist them in meeting their annual goals. This collaboration will continue.

The network works collaboratively with MA Advocates for Children to enhance post-secondary education opportunities for people with developmental disabilities. The network has been and will continue to facilitate the work of the Allies in Self-Advocacy State Team. The network will provide a forum and support to the team to address its goals and objectives developed at the Providence summit earlier this year. In addition, the network will hold a number of forums in the coming years targeting issues impacting people with developmental disabilities. The subjects for those forms will be determined in the fall after solicitation of stakeholder input is completed.

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

GOAL # 1: Transition

Youth with developmental disabilities will receive the supports they need to develop the prerequisite skills to live as adults.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|--|
| ☒ Quality Assurance | ☐ Outreach |
| ☒ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☐ Technical Assistance |
| ☐ Health | ☐ Supporting and Educating Communities |
| ☒ Employment | ☒ Interagency Collaboration and Coordination |
| ☐ Housing | ☐ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☒ Barrier Elimination |
| ☐ Recreation | ☒ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☒ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 400 youth with developmental disabilities will improve knowledge and skills needed for adult life by September 30, 2016.

Activities

1. Develop collaborative partnerships with secondary school systems to identify students and public colleges to provide locations and supports for trainings.
2. Increase from one training team by adding at least one SALS trainer and supporter certified to conduct youth in transition training.
3. Conduct youth in transition trainings.
4. Provide support to the annual Youth Leadership Forum (YLF).
5. Conduct follow-up activities to measure skill development.

Timeline

1. Completed. See FFY12 PPR.

2. Completed. See FFY12 PPR.
3. 10/1/11 - 9/30/16
4. 10/1/12 - 9/30/16
5. 1/1/12 - 9/30/16

Objectives

Standards for transition specialist qualifications will be adopted and implemented by the Department of Elementary and Secondary Education by September 30, 2016.

Activities

1. Award at least one grant to support advocacy efforts.
2. Collaborate with transition specialist stakeholders to ensure transition specialist qualifications meet the necessary standards.
3. Develop a position paper on transition services.
4. Educate and solicit the support of individuals, families, educators, policymakers and the general public on the benefits of transition specialist qualifications.
5. Coordinate advocacy activities with partners, educators, and policymakers to support transition specialist qualifications.

Timeline

1. Completed. See FFY12 PPR.
2. 10/1/11 - 9/30/16
3. Completed. See FFY13 PPR.
4. 4/1/13 - 9/30/16
5. 4/1/13 - 9/30/16

Objectives

The Chapter 766 Individual Education Plan process will be integrated with the Chapter 688 Individual Service Plan process through the Bridges to Success initiative by September 30, 2016.

Activities

1. Establish advocacy partnerships with the Disability Law Center (DLC), Arc and other transition advocates.
2. Develop a position paper on the importance of integrating Chapter 766 with Chapter 688.
3. Educate and solicit the support of individuals, families, providers and the general public on the benefits of Bridges to Success.
4. Coordinate advocacy activities with partners and policymakers for policy and budget initiatives that support the Bridges to Success initiative.

Timeline

1. Completed. See FFY12 PPR.
2. Completed. See FFY13 PPR.
3. 4/1/13 - 9/30/16
4. 4/1/13 - 9/30/16

Objectives

Short-term measurable objectives will be a requirement for all Individual Education Plans by September 30, 2016.

Activities

1. Establish advocacy partnerships with MA Advocates for Children, Disability Law Center and other transition advocates.
2. Develop a position paper on the benefits of utilizing short-term objectives for students in special education.
3. Educate and solicit the support of individuals, families, providers and the general public on the benefits of utilizing short-term objectives.
4. Coordinate advocacy activities with partners and policymakers to support utilizing short term objectives.

Timeline

1. Completed. See FFY12 PPR.
2. Completed. See FFY13 PPR.
3. 4/1/13 - 9/30/16
4. 4/1/13 – 9/30/16

Objectives

The number of students in the Inclusive Concurrent Enrollment program attending college and living on campus will increase from 0 to at least 10 students by September 30, 2016.

Activities

1. Develop Inclusive Concurrent Enrollment (ICE) advocacy partnerships with MAC, Institute for Community Inclusion and other DD/higher education advocacy groups.
2. Identify barriers and develop strategies to overcome the identified barriers.
3. Educate and solicit support of individuals, families, providers, policymakers and the general public on the benefits of expanding the Inclusive Concurrent Enrollment program to include residential colleges.
4. Coordinate advocacy activities with partners and policymakers.

5. Educate administrators at Institutes of Higher Education (IHE) about benefits and opportunities to include students w/DD in college dormitories.

Timeline

1. Completed. See FFY13 PPR.
2. By 9/30/16
3. 10/1/13 – 9/30/16
4. 10/1/13 – 9/30/16
5. 10/1/13 – 9/30/16

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

- ☒ State Protection and Advocacy System
- ☒ University Center(s)
- ☐ State DD Agency

MA Advocates for Children, Secondary School Systems, Higher Education Programs, Easter Seals, the National Youth Leadership Network, Partners for Youth with Disabilities, MA Advocates Standing Strong

GOAL # 2: Leadership

People with developmental disabilities will be actively engaged in leadership and systems advocacy.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|--|
| ☒ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☒ Technical Assistance |
| ☐ Health | ☐ Supporting and Educating Communities |
| ☐ Employment | ☐ Interagency Collaboration and Coordination |
| ☐ Housing | ☐ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☐ Barrier Elimination |
| ☐ Recreation | ☐ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☒ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 100 people with developmental disabilities will become leaders in disability advocacy by September 20, 2016..

Activities

1. Utilize multiple marketing strategies to connect to people with developmental disabilities.
2. Support opportunities for individuals to participate in leadership training opportunities.
3. Partner with the DD Network to support the Gopen Fellowship for people with developmental disabilities.
4. Establish working relationships with agencies and advocacy groups to identify individuals for SALS training.
5. Expand the number of SALS trainers and supporters certified to conduct adult SALS.
6. Train adults with developmental disabilities in SALS.
7. Support opportunities to actively engage in leadership and systems advocacy.

Timeline

1. 10/1/11 - 9/30/16
2. 10/1/11 - 9/30/16

3. 10/1/11 - 9/30/16
4. 10/1/11 – 9/30/16
5. Completed. See FFY13 PPR.
6. 10/1/11 - 9/30/16
7. 10/1/12 - 9/30/16

Objectives

A minimum of 400 people with developmental disabilities will engage in disability advocacy by September 30, 2016.

Activities

1. Partner with DD Network and DDS to support Allies in Self-advocacy State team.
2. Conduct Legislative Advocacy training to improve knowledge and skills about the legislative and budget process.
3. Support Massachusetts Advocates Standing Strong to conduct self-advocacy and related training.
4. Host annual Legislative reception to provide DD advocates opportunities for disability advocacy.

Timeline

1. 1/1/12 -9/30/16
2. 10/1/13 - 9/30/16
3. 10/1/12 - 9/30/16
4. 3/1/12 - 3/31/16

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

- ☒ State Protection and Advocacy System
- ☒ University Center(s)
- ☐ State DD Agency

MA Advocates Standing Strong, Arc Massachusetts, Local and Regional Self-advocacy groups, Local Community Organizations

GOAL # 3: Employment

People with developmental disabilities will have more opportunities to work in jobs that meet their career expectations.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|---|
| ☐ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☐ Technical Assistance |
| ☐ Health | ☐ Supporting and Educating Communities |
| ☒ Employment | ☒ Interagency Collaboration and Coordination |
| ☐ Housing | ☒ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☐ Barrier Elimination |
| ☐ Recreation | ☐ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☐ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 100 individuals with developmental disabilities will establish portfolios for competitive employment by September 30, 2016.

Activities

1. Partner with the Department of Developmental Services and MA Advocates Standing Strong to develop a coordinated plan for portfolio building training.
2. Collaborate with MA Rehabilitation Commission, Independent Living Centers, provider organizations, youth organizations and others to conduct outreach to people with developmental disabilities.
3. Conduct Portfolio Building trainings.

Timeline

1. Completed. See FFY12 PPR.
2. 10/1/12 – 9/30/15
3. 10/1/12 – 9/30/16

Objectives

A minimum of 50 people living with autism and other developmental disabilities will receive employment supports through various state agencies by September 30, 2016.

Activities

1. Educate and solicit the support of individuals, families, providers, policymakers and the general public on the benefits of Employment Supports.
2. Conduct coordinated advocacy activities with partners and policymakers.
3. Support budget and policy initiatives that enhance employment supports.
4. Advocate for the implementation of the Autism Commission recommendations related to employment services for people with autism.
5. Collaborate with various state agencies to develop and implement more comprehensive employment supports for people with autism/DD.

Timeline

1. 10/1/11 – 9/30/16
2. 10/1/12 – 9/30/16
3. 10/1/12 – 9/30/16
4. 1/1/13 – 9/30/16
5. 1/1/13 – 9/30/16

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

- ☐ State Protection and Advocacy System
- ☐ University Center(s)
- ☒ State DD Agency

MA Advocates Standing Strong, MA Rehabilitation Commission, Independent Living Centers, Autism Commission

GOAL # 4: Supporting Families

Families will have the supports they need to ensure fulfilling lives in the community for them and their children with developmental disabilities.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|--|
| ☐ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☐ Technical Assistance |
| ☐ Health | ☒ Supporting and Educating Communities |
| ☐ Employment | ☐ Interagency Collaboration and Coordination |
| ☐ Housing | ☐ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☐ Barrier Elimination |
| ☐ Recreation | ☐ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☒ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 100 families will pursue individualized family support services by September 30, 2016.

Activities

1. Establish advocacy partnerships with MA Families Organizing for Change, Arc Massachusetts and other advocacy groups.
2. Educate and solicit the support of individuals, families, providers, policymakers and the general public on the benefits of individualized Family Supports.
3. Support the education of under-served multicultural populations about family supports and other disability resources for their children with disabilities.
4. Support policy and budget initiatives, and conduct coordinated advocacy activities with partners and policymakers that enhance the use of and funding for family support.

Timeline

1. Completed. See FFY12 PPR.
2. 10/1/11 - 9/30/16

3. 10/1/12 – 9/30/16

4. 10/1/11 – 9/30/16

Objectives

A minimum of 200 families of persons with developmental disabilities will access information on respite options by September 30, 2016.

Activities

1. Conduct an analysis of the status of respite services in Massachusetts, including establishing a baseline of state budget dollars, availability, return on investment, best practices and success stories.
2. Collaborate with Statewide and National Respite Networks to develop a coordinated advocacy strategy to expand respite opportunities for people with developmental disabilities.
3. Partner with the Mass. Lifespan Respite Coalition to update and share web-based information about respite providers with family caregivers.
4. Support information and education sessions on respite options to individuals, families, providers, policymakers, and the general public.

Timeline

1. By 6/30/14
2. 10/1/11– 9/30/16
3. 10/1/13– 9/30/16
4. 10/1/13 - 9/30/16

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

- ☒ State Protection and Advocacy System
- ☐ University Center(s)
- ☐ State DD Agency

MA Families Organizing for Change, Arc Massachusetts, Mass. Lifespan Respite Coalition, New England Index, Executive Office of Elder Affairs, Massachusetts Sibling Support Network, Advocates for Autism in Massachusetts, the Mass. Down Syndrome Congress, Massachusetts Advocates Standing Strong, Disability Law Center, Federation for Children with Special Needs, UMass Medical Center, Early Intervention Coordinating Council

GOAL # 5: Homes

People with developmental disabilities will have more housing options for living independently in the community.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|--|
| ☐ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☐ Technical Assistance |
| ☐ Health | ☒ Supporting and Educating Communities |
| ☐ Employment | ☐ Interagency Collaboration and Coordination |
| ☒ Housing | ☐ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☐ Barrier Elimination |
| ☐ Recreation | ☐ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☒ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☒ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 100 individuals with developmental disabilities/families will pursue alternative housing options by September 30, 2016.

Activities

1. Conduct an analysis of existing research of the barriers to and utilization of alternative housing options and determine next steps.
2. Establish partnerships with organizations for enhancing the use of effective alternative models.
3. Support trainings and work with interested parties to pursue alternative options.
4. Educate and solicit the support of individuals, families, policymakers and the general public.
5. Support policy initiatives that expand the use of alternative housing options.

Timeline

1. Completed. See FFY13 PPR.
2. Completed. See FFY13 PPR.
3. 7/1/13 - 9/30/16
4. 10/1/11-9/30/16

Objectives

People with developmental disabilities in state school settings and their families will gain knowledge on the benefits to living in the community to help them transition to community living by September 30, 2016.

Activities

1. Conduct research about current training and resources provided to individuals and families.
2. Establish partnerships with MA Advocates Standing Strong, DDS and others to develop strategies to reach people.
3. Develop new resources or update existing resources.
4. Educate individuals, families, and the general public on the benefits of living in the community.
5. Support budget and policy initiatives that enhance community living opportunities for people with developmental disabilities.

Timeline

1. Completed. See FFY12 PPR.
2. Completed. See FFY13 PPR.
3. Completed. See FFY13 PPR.
4. 7/1/13 - 9/30/16
5. 10/1/11 - 9/30/16

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

- ☐ State Protection and Advocacy System
- ☐ University Center(s)
- ☒ State DD Agency

MA Advocates Standing Strong. MA Families Organizing for Change, Autism Housing Pathways, Citizens' Housing and Planning Association

GOAL # 6: Community Supports

People with developmental disabilities will have the services and supports they need to ensure fulfilling lives in the community.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|---|
| ☒ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☒ Technical Assistance |
| ☒ Health | ☐ Supporting and Educating Communities |
| ☐ Employment | ☒ Interagency Collaboration and Coordination |
| ☐ Housing | ☒ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☐ Barrier Elimination |
| ☐ Recreation | ☒ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☐ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 50 community based service programs will adopt and utilize best practices in Positive Behavioral Supports (PBS) by September 30, 2016.

Activities

1. Conduct research and compile documentation on the efficacy and effective use of PBS for people with DD.
2. Collaborate with DDS and other interested organizations to develop curriculum for PBS.
3. Educate and solicit support of people with developmental disabilities, families, providers, policymakers, general public.
4. Support the education of community based service providers on PBS.

Timeline

1. Completed. See FFY12 PPR.
2. Completed. See FFY13 PPR.
3. 10/1/12 – 9/30/16
5. 7/1/13 – 9/30/16

Objectives

A minimum of 500 individuals living with autism and their family members will have the information they need to access services and supports by September 30, 2016.

Activities

1. Conduct research- compile documentation on the current level of comprehensive community services and supports to people with autism in MA.
2. Advocate for implementation of the Autism Commission recommendations.
3. Conduct needs assessment on the 7 Autism Resource Centers and develop recommendations to strengthen and enhance the services offered.
4. Support the Autism Insurance Resource Center to expand resource information, technical assistance and referrals to people with autism.
5. Educate and solicit support of people with developmental disabilities, families, providers, policymakers, general public on meeting the needs of people with autism.
6. Support policy/ budget initiatives that increase services and supports for people with autism.

Timeline

1. Completed. See FFY13 PPR.
2. 1/1/13 – 9/30/16
3. 7/1/13 - 6/30/14
4. 10/1/12 - 9/30/16
5. 10/1/11 - 9/30/16
6. 10/1/11 - 9/30/16

Objectives

A minimum of 1000 people with developmental disabilities will have the information on human rights and safety they need to lead safe and productive lives in the community.

Activities

1. Partner with the Disability Law Center, MA Advocates Standing Strong, state agencies and other advocacy groups to develop a coordinated advocacy strategy to educate people with developmental disabilities and others on protecting human rights.
2. Conduct trainings with individuals with developmental disabilities on rights and protecting their safety.
3. Educate and solicit the support of individuals, families, providers, policymakers and the general public on improving safety of people with developmental disabilities.
4. Support a National Background Checks bill and other budget and policy initiatives that enhance the capacity to protect the rights and safety of people with DD.

Timeline

1. 10/1/11 - 9/30/16
2. 10/1/11 - 9/30/16
3. 10/1/11 - 9/30/16
4. 10/1/11 - 9/30/16

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

- ☒ State Protection and Advocacy System
- ☐ University Center(s)
- ☒ State DD Agency

MA Advocates Standing Strong, Autism Commission, Advocates for Autism MA, Asperger's Association of New England, Autism Insurance Resource Center, Executive Office of Public Safety and Security, the Executive Office of Health and Human Services, Department of Developmental Services, MA Down Syndrome Congress

GOAL # 7: Self-Determination

Individuals with developmental disabilities gain control and exercise self-direction in their lives.

Area(s) of Emphasis:

Strategies to be used in achieving this goal:

- | | |
|--|--|
| ☒ Quality Assurance | ☒ Outreach |
| ☐ Education and Early Intervention | ☒ Training |
| ☐ Child Care | ☐ Technical Assistance |
| ☐ Health | ☐ Supporting and Educating Communities |
| ☐ Employment | ☐ Interagency Collaboration and Coordination |
| ☐ Housing | ☐ Coordination with related Councils, Committees and Programs |
| ☐ Transportation | ☒ Barrier Elimination |
| ☐ Recreation | ☐ Systems Design and Redesign |
| ☒ Formal and Informal Community Supports | ☐ Coalition Development and Citizen Participation |
| | ☒ Informing Policymakers |
| | ☐ Demonstration of New Approaches to Services and Supports |
| | ☐ Other Activities |

Objectives

A minimum of 500 individuals with developmental disabilities shall have the choice of DDS services or qualified DDS providers and shall be able to change their services or service providers by September 30, 2016.

Activities

1. Collaborate with Mass. Alliance for 21st Century Disability Policy (MA21), DDS and others.
2. Support policy to enhance the use of self-directed supports. (If "Real Lives" legislation passes) Review and comment on new regulations, guidelines, procedures resulting from passage of "Real Lives" bill.
3. Develop training materials and educate and solicit the support of individuals, families, providers and policymakers on the principles of "Real Lives".
4. Advocate for policy and budget initiatives that support the Real Lives Initiative.

Timeline

1. 10/1/11 - 6/30/16
2. 10/1/13 - 9/30/16
3. 10/1/11 - 9/30/16

Objectives

A minimum of 50 Individuals with Developmental Disabilities will acquire skills needed for self-sufficiency through MDDC Independence College by September 30, 2016.

Activities

1. Establish training coordinator position at the Council.
2. Establish partnerships with MASS, DPPC, Easter Seals, Partners for Youth with Disabilities and others to combine training efforts under Independence College.
3. Work with partners to Develop a curriculum, establish credit values, etc.
4. Partner with colleges, business and others to expand opportunities for students.
5. Recruit and enroll students.
6. First class graduates from Independence College.
7. Second Class graduates from Independence College.

Timeline

1. Completed. See FFY12 PPR.
2. Completed. See FFY13 PPR.
3. By 6/30/2014
4. 10/1/12 - 9/30/16
5. 10/1/13 - 9/30/15
6. By 9/30/15
7. By 9/30/16

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

- ☒ State Protection and Advocacy System
- ☐ University Center(s)
- ☒ State DD Agency

Alliance for 21st Century Disability Policy, MA Advocates Standing Strong, Easter Seals, Post-secondary Institutions, The Arc of Massachusetts, Mass. Families Organizing for Change, Massachusetts Sibling Support Network, Advocates for Autism in Massachusetts, the Mass. Down Syndrome Congress, Disability Law Center, and the Federation for Children with Special Needs

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

- Outline how the Council will examine the progress made in achieving the goals of the State Plan.
- Explain the methodology, which may be qualitative or quantitative, that will be used to determine if the needs identified and discussed are being met and if the Council results are being achieved.
- Describe the Council's role in reviewing and commenting on progress towards reaching the goals of the Plan.
- Describe how the annual review will identify emerging trends and needs as a means for updating the Comprehensive Review and Analysis.

The Council utilizes the following terms to define the work that it engages in to meet DD Act requirements. Advocacy is the active support of policies and practices that promote self-determination and inclusion in the community for individuals with developmental disabilities and families, and related efforts that support self-advocacy activities toward the same end. Capacity Building is a process of activities that lead to improving the ability of individuals with developmental disabilities and their families to enhance self-determination, independence, productivity and inclusion, and/or enhance the capacity of the system of services and supports to enhance opportunities for them to do so. Systems Change is a process that fundamentally alters the way that a government, organization or community provides services and/or allocates resources in supporting citizens with developmental disabilities and their families.

All of the Council's State Plan Objectives have identified milestones to be accomplished. In 2013 the Council built on the State Plan activities framework to develop more detailed activities, outputs and outcomes to clearly identify success in reaching milestones and achieving objectives. Council staff and State Plan committee members participated in a 2 day workshop conducted by NACDD staff through the technical assistance contract to learn and implement strategies for effective evaluation and developing logic models. The logic model completed for each objective in the State Plan is attached. In addition, the Council will utilize a mechanism to gather qualitative feedback from our partners and individuals with developmental disabilities, families, advocates and others. This data and information will be used to confirm the achievement of our intended outcomes, to adjust strategies that have been ineffective and to share results and lessons learned. The Council will also utilize ongoing satisfaction surveys to track whether achievement of milestones is having the intended positive effect on the lives of individuals with developmental disabilities and families.

The Council will use multiple strategies for determining if needs are being met and results achieved. Our success is determined by our ability to effectively achieve milestones toward the targeted outcomes in a timely manner. It is critical that activities are monitored on a consistent basis. The Council utilizes the DD Suite Data Management system to develop the framework for all projects, including the State Plan goals and objectives each project targets, the specifications for project implementation and the specific target populations and resources dedicated to the project. The DD Suite also provides a mechanism for reporting progress toward achieving short and long-term outcomes, and the measures that will be utilized to determine success in achieving targeted outcomes. All projects and activities entered into the DD Suite are directly linked to the State Plan goals and objectives. This provides a continuous mechanism for reviewing the status of activities and milestones toward addressing and achieving any objective at any time.

Council members and staff are also engaged in a variety of activities that support achievement of our goals and objectives. Much of the work delineated in the State Plan relies on the efforts of members and staff engaged in research, developing reports, partnership building and advocacy. This work involves many inter-agency and collaborative endeavors and public education efforts. In addition, the Council often works in the role of convener, bringing diverse groups together toward a common objective. All Council member and staff (non-grant) activities addressing State Plan goals and objectives are also managed and monitored in the

DD Suite. These projects utilize similar methodologies for reporting progress toward achieving short and long-term outcomes and the measures that will be utilized to determine success.

Satisfaction surveys and focus groups are utilized to support whether the milestones and targeted outcomes have actually led to the intended positive effect on the lives of individuals with developmental disabilities and families. Surveys are collected on an ongoing basis and focus groups convened with partners and other interested parties as appropriate.

The State Plan Committee will have primary responsibility for reviewing the measures of success and qualitative feedback, and recommending changes in goals, objectives and strategies to the Council. The DD Suite generates status reports on all Council projects and is used as the basis for committee review and deliberation. This information is combined with feedback from satisfaction surveys and focus groups to provide the committee with both quantitative and qualitative information.

The Council considers the State Plan to be a working document that is subject to change as circumstances change. Staff reports the status of grant projects addressing the State Plan objectives at all Council meetings. In addition, wherever possible Council members are matched with grant projects that are consistent with their interests and provide status reports to the membership. Council member and staff activities addressing the State Plan objectives are reported by the individual with primary responsibility for the activity. This information is used by the Council to identify any potential changes to the goals and objectives that projects target, changes in specifications for project implementation or resource allocations to projects.

The Council conducts a complete review of all projects and activities to determine progress toward meeting the goals and objectives. This review is conducted on an ongoing basis throughout the year. State Plan Committee meetings, reports at all Council meetings, grantee evaluations and stakeholder feedback all contribute to a continuous evaluation process.

In January the Council reviews and analyzes the results from the previous year's Annual Program Performance Report. In March each year the Council initiates a review of new and updated research, reports and data, completes a mid-year review of satisfaction surveys and solicits input from policymakers. The State Plan Committee reviews all input and develops recommendations for potential amendments to the State Plan. These recommendations are distributed for public input and then deliberated at the June Council meeting. Amendments to the state plan goals and objectives approved by the Council for the next fiscal year are distributed for additional public comment.

ATTACHMENTS:

2014 State Plan Logic Model.docx

FFY 2014 Logic Model

FFY 14 State_Plan_Amendment_Updates - MA.doc

2014 State Plan Amendments Checklist

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

Goal	Subtitle B \$	Non-Federal Share \$	Total \$
1. Community Supports	132,247	32,368	164,615
2. Employment	123,102	34,497	157,599
3. Homes	125,709	32,151	157,860
4. Leadership	159,482	43,570	203,052
5. Self-Determination	160,229	42,743	202,972
6. Supporting Families	119,392	27,601	146,993
7. Transition	223,916	63,046	286,962
8. General Management	276,355	52,233	328,588
9. Functions of the DSA	0	0	0
10. TOTALS	1,320,432	328,209	1,648,641

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) to (N) in the Developmental Disabilities Assurance and Bill of Rights Act.

☒ Assurances submitted

Approving Officials for Assurances

☒ For the Council (Chairperson)

☐ 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 State Plan Committee developed recommended changes to the Council's State Plan goals and objectives. These proposed changes were presented to and approved by the full Council on June 11, 2013. They were published to the Council's website and availability for comment was posted on Facebook and announced through the extensive Council, DD Network, grantee and advocacy partner e-mail distribution lists. Respondents were instructed to comment on any suggested changes in goals and objectives, and to provide ideas for activities that could be undertaken and information on organizations the Council may want to connect with in addressing the a particular objective. Interested parties could submit comments by e-mail, fax or in writing until September 30th (extended from August 11th). No comments or recommendations requesting substantive changes were received.

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

No significant comments were received through the public input process. No revisions were made to the State Plan goals and objectives for 2014 as a result of public input. Upon completion of the FFY 2013 PPR the state plan committee reviewed and approved minor edits to some activities under the objectives. No substantive changes were recommended or made to the FFY 14 State Plan.