

Meeting The Challenge of The Community Imperative

Massachusetts Department of Developmental Services System Initiatives

Introduction

Over the last 45 years, the Massachusetts Department of Developmental Services (the Department) has built a sophisticated community-based service system, moving from a state agency that served more than 10,000 individuals in nine large institutional settings, to an agency that serves more than 36,000 individuals supported in a variety of community settings. In addition to the expansion of Department services, the public education and broader human service system evolved during those same 45 years. A child born in 2016 with a developmental disability (DD) can receive early intervention services from birth to age 3, special education in local school systems from age 3 through 22, and adult services from the Department and state agencies, including among others, MassHealth, for the rest of the person's life. The mission of the Department has, and continues to be, the provision of supports that address individual needs based on a person centered plan and that are provided in ways that draw upon a person's gifts while promoting full engagement as a contributing member of a local community. The ultimate goal is to enable individuals the Department supports feel valued, have lives that are rich in experiences and which have a bounty of friendships and relationships. *(DDS Mission and Guiding Principles: <http://www.mass.gov/eohhs/gov/departments/dds/developmental-services-mission-statement.html>)*

Despite the move toward community-based services, the people the Department supports are "in" communities but too often are not yet "of" the community. Much of a person's time is spent with paid staff and family members. They often do things in groups and in ways that separate them from the community around them. To achieve the "ultimate goal" described above, the Department recognizes the need to take steps that will move the system into the next stage of its evolution. Just as moving individuals from institutions into community settings was once a new frontier, so too is bringing individuals into the real mainstream of community life with their fellow citizens. The initiatives outlined below describe steps the Department is taking to create conditions for people to have better lives as fully engaged members of their community. Fostering those conditions will depend upon the continuation of the positive and open working relationship the Department has with all of its stakeholders. Together we can succeed in making the kind of transformation we are seeking.

The Employment Blueprint

Having a full or part time job creates a feeling of self-worth for everyone, but it can be especially important for the individuals the Department supports. A job can lead to a better sense of one's own identity and can create a pathway to developing friendships with co-workers. Both create the kind of valued role we seek for everyone the Department serves.

In August 2013, the Department initiated a series of meetings with representatives of the Association of Developmental Disability Providers (ADDP) and The Arc of Massachusetts with the purpose of laying out a plan to transform day and employment services in a way that would better address the Employment First Policy (<http://www.mass.gov/eohhs/gov/laws-regs/dds/policies/s-employment-first-policy-2010-2.html>) already in place. In November 2013, consensus was reached on an Employment Blueprint (<http://www.mass.gov/eohhs/docs/dmr/blueprint-for-success.pdf>) that set ambitious goals to accomplish over a 4-year period. One of the goals in the Plan to close all sheltered workshops will be accomplished by the end of fiscal year 2016. A critical action step was to partner with the Institute for Community Inclusion/University of Massachusetts/Boston (<http://www.communityinclusion.org/>) to provide training and consultation so that providers could access resources to guide needed changes in their programs. Future emphasis will be placed on ensuring that group employment sites are truly integrated in typical settings, and that as many people as possible in those settings, or in individual integrated jobs (the preferred option) are earning minimum wage or better by the end of fiscal year 2018. In addition, as workshops closed, many individuals moved to community-based day services where the focus is on career planning and job exploration. Now there is a need to provide resources to ensure those services are integrated in the community and actively provide pathways to employment and/or to provide productive use of a person's time when not working.

Family Support Enhancement

Families are the largest group of primary caregivers of individuals who are supported by the Department. The Department provides or arranges for day and employment support, and transportation for adults living at home, so that families can count on their son or daughter being productively occupied for approximately 30 hours a week. This enables family members to continue to hold jobs much like they did during the years their child was attending public school. Approximately 11,000 families receive a modest amount of family support funding that helps sustain them in their caregiving role. Respite care, so that family members get a break from their day-in day-out support role, is a service highly valued by families. Families also use funding to access local resources such as memberships to the YMCA or dues to be part of a service organization. From talking with families and examining internal data, the Department is very aware that many families need more support than is offered at this time. More than 9,000 families currently receive no direct family support funding and those who do receive funding often need more. This is the most cost effective service the Department provides when one considers the cost to provide out of home residential support to individuals instead of remaining in a well-supported family home, especially when families want to live together. Additionally, maintaining a family's ability to support a family member in their own home often leads to some of the best outcomes. DDS is committed to work with families and stakeholder groups to preserve and expand funding in the future. The Department is very pleased that both the Governor's and the House of Representatives budget for FY'17 includes increased funding to support families. (*FY16 Family Support Plan* <http://www.mass.gov/eohhs/docs/dmr/reports/family-support/annual-plan-family-support-fy16.pdf>)

The Campaign for Shared Living

Shared Living is a residential model that enables an individual to move into the home of a community member who provides on-going support as indicated in the person's Individual Support Plan. There are a number of qualified Shared Living provider agencies who contract with the Department to recruit, screen, train and then match potential community members with individuals who are in need of and choose this service. Once a placement is made the agency is responsible for monitoring and supporting the person and the family with whom they live. The Shared Living model can provide individually tailored support and shared living providers can become a gateway to social inclusion through their own network of family members, friends and community associations.

Based on national data that indicates Massachusetts utilizes shared living services far less than many other states, as well as demographic studies that indicate there will be a potential lack of workers to staff community residences in the future, in January 2015, the Department, along with provider agency representatives, sought ways to better educate individuals, family members, and Department staff to promote the expanded use of this service model. In addition, the competing needs of other residential service agencies, such as those that serve the elderly, will place greater demand on the shrinking pool of direct service workers. For all of these reasons The Campaign for Shared Living (<http://www.addp.org/sites/default/files/Shared%20Living%20Brochure%20Inside%201.pdf>) launched with a goal of increasing the number of people who take advantage of this arrangement over the next four years. By doing so, the Department will slow the rate of growth and cost of new community residences while increasing the number of shared living opportunities that provide high quality service and are cost effective.

The expansion of Shared Living is part of a larger work initiative to reconfigure the existing residential support system in ways that promote a more person centered and more cost efficient approach to supporting people in their communities. Models other than Shared Living that are part of this planning effort include:

- intensive family support so a person can remain at home;
- self-directed approaches such as Person Directed Programs or use of Agency with Choice;
- individual supports that enable a person to live in their apartment or home;
- use of Medicaid-funded supports such as Adult Family Care and Personal Care Assistance services.

Self Determination

In 2014 legislation known as The Real Lives Bill (<http://static1.squarespace.com/static/518bb7cde4b0d1e7bd9c37b5/t/54d25624e4b08d5997c6b92b/1423070756244/hb4237-real-lives.pdf>) set out a broad outline and a number of specific tasks for the Department and other agencies to complete to enhance participant direction options where individuals can have control over an allocation of funding to arrange their own

customized supports and the authority to hire and fire the staff who provide those supports.

There are two methods by which individuals can choose to self-direct their services:

- a Person Directed Program (PDP) that uses a fiscal intermediary to process spending to pay for staff;
- an Agency With Choice whereby certain qualified provider agencies will act as a co-employer of staff that are jointly hired to provide support.

The Department is taking a number of steps to help ensure the integration and full support of these options for the people it supports including establishment of the Advisory Board mandated in the Law that has helped develop procedures and informational materials as part of this initiative. A manager has been hired in each of the four Regions to provide support to Area Office Service Coordinators who will then be better able to offer these options and know how to assist individuals and families if they decide to use them. An agreement is also in place with the union that represents service coordinators to allow caseload size adjustments due to the added time it takes to serve as a service broker for those choosing the PDP model. In addition, the Department has initiated a work group to provide guidance to participants, providers and Department field staff in order to promote increased use of the Agency With Choice model.

The Department's ultimate goal is to significantly increase the number of people who self-direct their services in FY'17 and beyond.

Compliance with Social Integration Rules

The Department receives federal reimbursement for services by participating in the Home and Community Based Services (HCBS) Medicaid Waiver Program. In order to receive this funding certain assurances must be met based on standards issued by the Center for Medicare and Medicaid Services (CMS). For fiscal year 2017, the Department will claim over \$600 Million in revenue, the majority of which is generated through the waiver program. The Department has been able to prevent service reductions in difficult fiscal times by maximizing federal contributions making it essential that we continue to meet HCBS federal standards over time.

In 2014, CMS issued a new set of rules related to all settings where HCBS waiver services are delivered (<https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>). Essentially it is the federal government's version of "addressing the community imperative," by prescribing a set of outcomes that deal with social integration and personal control that must be achieved by March 17, 2019. Massachusetts developed a transition plan, required by CMS, that has been submitted to CMS, and is currently undergoing revisions based on CMS feedback. Some key action steps that are being taken to comply with the new standards include:

- working closely with all providers to enhance outcomes for individuals;

- working with 14 specific residential programs on strategic plans that will lead to meeting the established outcomes despite being in physical settings that present challenges;
- developing a new standard licensing and certification tool to assess compliance with the new community integration standards;
- issuing Departmental policy that prevents development of any new "campus" based programs and limits capacity in those that are currently in operation; and
- closely tracking the progress relative to day and employment programs as outlined in The Employment Blueprint.

Creating Our Common Wealth

In partnership with the Center for Developmental Disability Evaluation and Research/University of Massachusetts Medical School, the Department is in the midst of implementing an initiative for 100 emerging leaders from provider organizations, the Department and advocacy organizations. The stated purpose of the initiative is "to foster leadership committed to increasing social inclusion, freely-given friendships and other meaningful relationships between people with and without disabilities... in a way that promotes innovation; provides invitation, direction and encouragement; generates collective learning; and creates and strengthens personal and professional bonds... so that over time communities embrace the gifts, talents and capacities of citizens of all abilities."

The initiative's overall goal is to prepare participants to step into influential leadership roles in all sectors of the service system. A major focus of the effort is to ensure that the participants are imbued with values and strategies to address the challenges that come with meeting the community imperative of social integration and personal control. The process includes a series of large group meetings featuring nationally recognized consultants, such as Beth Mount and John O'Brien, combined with regional support groups where participants share the progress on projects they have developed to further social integration.

Widening The Circle

The Department has contracted for a number of years with the Arc of Massachusetts to provide consultation, training and informational materials in order to help create conditions that will lead to individuals developing and maintaining friendships outside their usual circle of peers, staff and family members (<http://thearcofmass.org/programswidening-the-circle/>) The goal is to reduce the loneliness and isolation that has been consistently mentioned as an issue by individuals and families in various surveys. Research indicates that having friends is important for one's health and overall happiness. Friendships also provide a natural safeguard for those we support by watching out for and assisting individuals during difficult times. Most recently a "Toolkit" on how to make friends on the job was developed and more tools are planned for other settings. (http://thearcofmass.org/wp-content/uploads/2015/12/FRIENDSHIPS-AT-WORK-TOOLKIT_Final_1-5-2016.pdf)

Positive Behavioral Supports

The Department has been moving away from a clinical approach of managing people's behavior to a "Positive Behavioral Support" approach where emphasis is placed on gaining a broad understanding about the meaning of behavior and its function. This approach builds on the principles of choice, self-determination and person centered planning to enhance a person's quality of life. The goal is to achieve meaningful social outcomes that will lead to a person being able to become better engaged with their community. (<http://ddslearning.com/dds-pbs-initiative/>)

Development of a formal Department Policy on Social Inclusion

The Department is working with the Center for Developmental Disability Evaluation and Research/University of Massachusetts Medical School to assist in the development of a formal policy on social inclusion. A series of focus groups are planned with a variety of stakeholder vantage points (individual, family, staff, administration) to gain insight about ways to facilitate social inclusion. Key aspects that will be looked at are regulations, policies, procedures and rules that are in place that actually create barriers to social inclusion. The goal is to reach consensus on a policy that balances risk and opportunity and that offers guidance on this important subject.

Provision of services to people with Autism, Prader-Willi and Smith-Magenis Syndrome

The Department has embraced the opportunity to welcome people with Autism and Prader-Willi Syndrome who do not have an Intellectual Disability and those with Smith-Magenis Syndrome into the community of those we support.

More than 605 people have been made eligible for services since November 2014. Many people have accessed services the Department currently provides while others have identified the need for the Department to develop new services, including coaching, employment supports, social skills training and housing supports specifically designed to meet their needs and ensure that they are active participants in the Commonwealth's communities.

The Department is working closely with other state agencies, in particular, EOHHS, the Department of Mental Health, the Massachusetts Rehabilitation Commission and MassHealth to address people's service needs. We look forward to working with the Autism Commission to improve services to both newly eligible people as well as to those who have been served in our existing system over the years.

Services to People with Acquired Brain Injury

The Department is working with EOHHS and MRC to address requirements in the Hutchinson Settlement Agreement. This agreement resulted from a class action law suit brought on behalf of individuals with Acquired Brain Injury (ABI) who live in nursing facilities and chronic care hospitals. Specifically, the Department is responsible for creating and providing 24 hour residential support options for members of the "class" who are in need of that service with funding provided by MassHealth. More than 280 people are now served in the community in residences operated by our private sector providers.

Aging

Approximately 9,000 people DDS supports are age 50 or older and living in the community. The Department convened a wide range of stakeholders to identify issues and develop strategies to address the needs of this group in the areas of alternative programs and services, health care and end of life planning. Among the initiatives being implemented in the near future, 13 provider agencies will open Memory Cafes designed to provide an opportunity for both a person with dementia and their caregiver to socialize and enjoy time with others experiencing the same challenges.

Summary

In closing, Massachusetts takes pride in the robust system of community supports that has developed over the past 45 years and maintains a strong commitment to innovation and developing new ways of offering supports that promotes full social integration, valued roles, and membership in the community for the individuals we support. We are determined to continue to move forward with individuals, family members, and community partners to make changes that will improve the lives of all those we support.

Many thanks for all you do each day to support this mission.