

**Department of Developmental Services
Annual Family Support Plan
Fiscal Year '18 (July 1st, 2017 – June 30th, 2018)**

Human Service Agency Overview of Family Support

A. Background

The Department of Developmental Services (DDS) has been providing flexible family support services since 1995 to children and adults eligible for services from DDS who are living at home with their families. This is the fifteenth Annual Plan for Family Support submitted by the Department as required by Chapter 171 of the Acts of 2002, "An Act Providing Support to Individuals with Disabilities and Their Families."

DDS is organized into four regions and 23 Area Offices managed by Regional Directors and Area Directors respectively, all under the auspices of Central Office. Each DDS region has a Director of Family Support. Area Office Service Coordinators provide assistance and supports to individuals/families, with a Children's Coordinator who usually works with children under the age of 18 years and their families, and a Transition Coordinator who usually works with individuals between the ages of 18 and 22 who are in the process of transitioning from school to adult services. Individuals over the age of 22 who have met the adult eligibility criteria for DDS services are assigned a Service Coordinator and participate in an Individual Support Planning (ISP) process.

B. Overview of Family Support

The primary goal of family support is to provide a variety of options to individuals with disabilities and their families that enable them to stay together and to be welcomed, contributing members in their home communities. The DDS Family Support system is based on the principle that individuals and families know their own needs. For this reason, and because of the individuality of each family, the range of services available under the program is broad. This approach allows families the flexibility to identify the resources that will be most helpful to support their family member in her/his home. The Family Support Centers and other family support programs are designed to be responsive to the dynamic and changing needs of the individual with a disability and his/her developmental stages throughout the lifespan within the family unit.

Guiding Principles for Family Support serve as the foundation for the delivery of services through the Family Support Centers and all of the family support program services funded by DDS.

Family support strives to achieve the goal of helping families stay together through:

- ❖ Developing families' natural capacities to meet the needs of family members;
- ❖ Offering additional supports such as staff resources, goods and services, and financial assistance; and
- ❖ Enhancing the capacity of communities to value and support people with disabilities and their families.

DDS receives specific funding designated for the delivery of family support services through the Family Support Appropriation Account in the state budget. The FY 2018 budget appropriation is \$63,532,818 million dollars. This appropriation amount provides consistent level of funding from FY '17 when DDS received an increase of \$5 million dollars in expansion funding. Of this total appropriation, approximately \$53 million is for specific family support services, and the remainder for other community support services. As a result of the expansion funding last fiscal

year DDS was able to provide a more robust array of in-home and community supports for more than 475 older caregivers committed to continuing to care for their adult family member at home, as well as individual flexible funding allocations for respite or other supports to about 2,000 families of both children and adults. The array of family support services provided with this funding is described in more detail in Section III, Family Support Resources and Funding.

A campaign on “Supporting Families” was initiated two years ago by The Arc of Massachusetts with the assistance of many partners including Massachusetts Families Organizing for Change (MFOFC), the Association of Developmental Disability Providers (ADDP), and Advocates for Autism of Massachusetts (AFAM). This campaign has developed information about the needs of caregivers, the impact of providing 24/7 care, and the cost-benefits to the state of providing supports to families as a means to avoid more costly out-of-home supports. This information is complemented by many powerful personal stories shared by families about the day-to-day challenges they face and the ways family support services and programs have made a positive and significant difference in their lives. The activities of this campaign contributed to an increased understanding of the need for and benefit of family support which was helpful in obtaining increased funding for these services in FY '17.

Based on June 2017 data, there are currently 37,952 individuals eligible for DDS services living in the community, with 8,333 children under the age of eighteen; 4,170 individuals between the ages of eighteen to twenty-two, and 25,449 over the age of twenty-two.. Approximately 20,000 children and adults are living at home with their families. With the passage of the Autism Omnibus Act in 2014, eligibility for DDS adult services was expanded to include adults with Autism Spectrum Disorders (ASD), Prader-Willi Syndrome, and Smith-Magenis Syndrome. Meeting the IQ (Intelligent Quotient) criterion is not a requirement for this group of individuals, but they must meet specific diagnostic criteria as well as the standard of having a Developmental Disability which includes substantial functional impairments in three or more of seven life areas. Currently there are approximately 1,205 individuals with ASD who have been found eligible for adult services, and 4 individuals with Prader-Willi Syndrome. Of this total, 578 are between the ages of 18 through 21, and 627 are age 22 and older. These individuals eligible for adult services have access to an array of community support services including: employment/day services, family supports, in-home skills training and community integration supports, and individual supports for people who are living more independently. It has been more challenging to engage this new group of adults with ASD in accessing services and DDS is continuing to explore new service models. However, there is a higher percentage of these adults who are selecting to self-direct their services through the Participant-Directed Program or Agency With Choice models, which is a positive trend.

C. Process for obtaining substantial input from families on current family support services

DDS uses multiple approaches, both formal and informal, to seek input and guidance from individuals with intellectual disabilities and their families in order to help assess the Department's current system of family support services, and help inform policy development and future directions. Over the past several years DDS, in partnership with family members and providers, has been engaged in a variety of initiatives to strengthen the information, resources, and assistance provided to families in their caregiving role that are directly responsive to priority need areas identified by families through a strategic planning process initiated in 2011, and described in the 2012 report *In Their Own Words: The Need for Family Support Services.* The important supports needed by caregivers and the benefits and cost-effectiveness of family support were identified. Families expressed the need for respite, access to flexible

funding/stipend resources, increased options for social and recreational experiences, and easier access to information along with help navigating services. As documented in this report, Family Support is 75% to 80% less expensive than providing services to an individual in an out-of-home residential placement.

A full copy of the report, *"In Their Own Words: The Need for Family Support Services"* and the plan *"Moving Forward in Enhancing Supports for Families: An Action Plan for Family Support,"* are available on the DDS website at: www.mass.gov/dds.

There are several longstanding approaches that DDS has established to gather input and obtain feedback from families and other stakeholders. These are described below.

The **Statewide Family Support Council**, comprised of parents from across the state who have, or recently had children and adult family members with disabilities living at home with them, provides a substantive and ongoing vehicle for input and consultation to the Commissioner on family support services, practices, policies, and needs. Council members have played integral roles in family support strategic planning processes, helped shape the procurement of family support services, been active participants in different workgroups, and will continue to have an important role in assisting DDS along with other stakeholders, in the implementation of specific recommendations and action steps designed to build a more comprehensive, coordinated and responsive system of supports.

There is regular information-sharing, discussion, and solicitation of input from the DDS **Statewide Advisory Council (SAC)** and the four regional and twenty-three area office **Citizen Advisory Boards (CABs)**. These advisory groups play an important role in helping to inform and educate the public and other decision-makers about the needs of individuals and families and the importance and benefits of the flexible services and supports that are provided. Additionally, information and updates about family support services is one of the topical areas discussed at the annual retreat held for SAC and CAB members in October.

The Commissioner along with other leadership staff meet with representatives of other family and individual advocacy organizations to seek input and obtain feedback on services and future directions. This includes representatives from the Arc of Massachusetts, Massachusetts Families Organizing for Change (MFOFC), Advocates for Autism in Massachusetts (AFAM), Massachusetts Advocates Standing Strong (MASS), Massachusetts Down Syndrome Congress, and the Developmental Disabilities Council. Regular meetings are also held with the leadership of the Association of Developmental Disability Providers (ADDP). Additionally, DDS leadership staff are actively engaged with the Autism Commission to work on plans and implementation of key recommendations in the Autism Commission Report that was released in March 2013, and the more recent Autism Omnibus Act signed into law in 2014.

D. Focus Areas: Review of Activities and Accomplishments in FY 2015 and Proposed Initiatives for FY 2017.

The following section provides brief highlights of ongoing efforts as well as new activities the Department has undertaken this past year, and includes where relevant, initiatives for development in the upcoming fiscal year.

I. Family Empowerment

What is the agency currently doing to promote or enhance family input or direction in the development of agency policies and procedures, program development, and evaluation of services?

DDS seeks input from individuals and families about agency services and new directions both formally and informally through a variety of organized groups and mechanisms, and this has informed and helped shape programmatic directions and priority areas in supporting families caring for their loved one at home. Family members are central participants on the statewide Self-Determination Advisory Board established to support implementation of the Real Lives legislation in 2014, and also were integral members of the Advisory Committee for the Positive Behavioral Supports Initiative that helped explore and develop a framework for the implementation of Positive Behavioral Supports (PBS) throughout the DDS system.

Individuals with disabilities and family members participate on the Department's Statewide Quality Council to assist in reviewing evaluation data and information about the quality of services provided, and to identify areas for development as part of a continuous quality improvement process. Family member engagement, input and participation is central to many of the agency-wide initiatives the Department is embarked upon, such as the *Employment First: Blueprint for Success and Shared Living Initiative*, so that the voices, preferences and concerns of families are understood and addressed as new service delivery approaches are pursued.

How will agencies change how they are currently doing business to make their agency and services more family-friendly and provide opportunities for families and individuals to have greater input and influence?

The family support services provided by DDS are based on the principles that individuals and their families are recognized as primary decision makers about their lives and supports, and options need to be flexible to be responsive to the unique needs, strengths and cultural values of families.

- DDS is updating the *Family Support Guidelines and Program Manual* which serves as the framework for the delivery of family support services, including specific guidance about the administration of individual flexible funding allocations/stipend resources and the goods and services that are allowable. The flexible funding resources made available by DDS provide families with choice and flexibility about the types of assistance that will be of greatest benefit to their family. DDS will continue to seek input from family members and other interested groups to address areas that need clarification as well as ways to promote responsiveness and flexibility while striking balance with reporting requirements and accountability.
- DDS offers two different approaches that enable individuals and families to engage in self-directing their services. The *Agency With Choice (AWC)* model, or the Participant-Directed Program (PDP) in which services are administered through use of a contracted *Fiscal Management Service*, allow individuals and families more control in service design, hiring of staff, and management of their budget. Regional Self-Determination manager positions have been established to help promote these models and support the increased participation of families and individuals to engage in directing their own services- a powerful way to exercise empowerment. Presentations on how these models work, and the successful experiences of individuals and families who engage in participant-directed services are offered on a regular basis, combined with other informational and resource materials to encourage use of self-directed service options. Ongoing education, support, and development of consumer-friendly informational materials will be provided. As of June 2017, there are 376 individuals/families using the Agency With Choice model, and 568 individuals/families engaged in self-direction through the Participant-Directed Program. There is a higher percentage of the newly eligible adults with ASD who are choosing one of these self-direction service approaches which is a positive trend.

- Two of the specialized programs for children/young adults, the DESE/DDS Program and the Autism Waiver Program, are structured to support family empowerment as they provide families the opportunities to direct service and budget planning to meet the needs of their child and family, and have a role in the selection of staff who will provide supports.
- The DDS Home and Community Based Waiver Programs for adults provide enhanced opportunities for individual and family empowerment, through increased choice in service providers, choice of service delivery method, and portability of services. Information and education continue to be offered through Service Coordinators along with other approaches to help ensure individuals and families are aware of the options available, and to support them to exercise their rights and choices when they are involved in service planning

II. Family Leadership

What training opportunities does the agency currently offer to families/individuals that would enhance their repertoire of skills?

DDS funds five regional Family Leadership programs and partners with Massachusetts Families Organizing for Change (MFOFC) to provide education, leadership training, and mentoring for families of children and adults with disabilities. This training and mentoring is developed and provided by families who have a family member with a disability, an important aspect of these programs. One primary vehicle for family leadership development is the sponsorship of a *Family Leadership Series*, which occurs across 6-8 days over a several month period. This past year, five regional Leadership Series were held providing leadership development to approximately 125 families. Many graduates of this series frequently move into new leadership roles in a variety of capacities and play active and effective roles in helping shape new initiatives. Each of the regional programs also sponsor a training series called “A Full Life Ahead” that offers monthly seminars for families on topics related to a variety of services and supports including sexuality, self-direction, person-centered planning, transition, housing, alternatives to guardianship, employment, futures planning, and fostering friendships. This series reaches between 450 to 500 families across the state, and since its inception in 2013 have reached more than 2,200 people.

An Advocacy Boot Camp has been developed to meet the needs of families with young children (birth to age 10), with developmental disabilities, chronic illnesses, and or complex medical needs. Six in-person sessions are held with content focused on building foundational advocacy skills so participants can empower their children to lead rich, meaningful, and exciting lives. Twenty parents participated in this training opportunity last fiscal year. Other highlights this past year include a full day conference for families focused on housing and creating a home of your own with 180 family members and professionals in attendance, a conference on transition to adult services in the northeast region, and several workshops focused on cultural brokering and partnering with families across cultures. There have been strategic and successful efforts to increase participation in regional leadership training events by families from diverse cultural and linguistic communities which has resulted in participation by families who speak more than 10 different languages. It has been an exciting and positive development to have a more diverse array of leadership training options available that are tailored to the needs of family member participants at different life stages and with different interests, needs and time availability.

Based on the premise that information is power, the DDS funded Family Support and Autism Support Centers provide an array of educational events and trainings on relevant topics of

interest to families of both children and adults, These Centers are required to offer a minimum of six training events per year, with many offering additional training opportunities. Leadership development is also promoted through the Centers by facilitating parent networking and mentoring, sponsoring parent support groups and one-to-one parent connections, grandparent support groups, and sibling support opportunities.

What new ideas or proposals would the agency initiate to give families/individuals more opportunities to develop and/or exercise their leadership skills?

DDS has initiated a leadership development initiative, *Creating Our Commonwealth*, now entering its third and final year, which provides training opportunities with both national and local experts on leadership skills and strategies, and best practices to promote social inclusion and community membership for individuals with Intellectual and Developmental Disabilities through innovative supports and service design. This initiative involves approximately 75 to 100 emerging leaders that include family members, provider staff, DDS staff, and individuals with disabilities. In addition to these training opportunities, participants engage in regional group meetings, have access to other experiential learning opportunities, and are required to develop a project that applies their new learning in a way that will facilitate community membership and new relationships for a group of individuals with disabilities.

Families have opportunities to further develop and/or exercise their leadership skills as members of the DDS Statewide Advisory Council and twenty-three Citizen Advisory Boards, through participation in the DDS funded Family Leadership Projects, as well as through the Family Support and Autism Support Centers which are expected to actively engage families and seek their consultation to identify interests and needs in developing activities and the array of service options they will offer.

Individuals with intellectual disabilities and family members play an important role in making presentations as part of the Department's orientation and training for new staff which reaches both departmental and provider staff, as well as in other conferences and training events. Sharing information about their experiences, perspectives, and what is most supportive and helpful to them, provides both a positive learning experience for staff and a way for individual and families to expand their own repertoire of skills.

Peer Support and Family Training, two services available through the DDS Home and Community-Based Waiver Programs, provide interested and qualified individuals and families the opportunity to provide training and mentoring to others, as well as provide learning opportunities for self-advocates and families who want to enhance their own leadership skills.

III. Family Support Resources and Funding

What are the current resources/funding that the agency allocates to family support? What are ways that the agency provides flexible funding to families that allow them to customize their services?

DDS funds **Family Support Centers** across the state intended to establish a local community presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults eligible for DDS services. Centers are expected to develop strong local affiliations and partnerships with other state and community agencies, become experts in generic resources and services, and work to maximize natural supports. Services provided include: information and referral, support groups, family trainings, parent

networking and mentoring, facilitation of social/recreational events, among other activities. Centers also provide Service Navigation that includes individualized and comprehensive information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving and help them navigate the service system. Centers administer flexible funding/stipends to families who are prioritized to receive an individual allocation which can be used flexibly by families to purchase allowable services and goods as defined in the Department's Addendum to the Family Support Guidelines and Procedures. There are 34 Centers funded across the State with funding totaling approximately \$10.4 million dollars. These Centers along with the Cultural/Linguistic Specific Centers described below provide some type of individualized assistance to about 11,000 families a year, plus reach many more through information and referral, trainings and recreational and community events. These Centers also administered about \$6 million dollars in flexible funding allocations to families.

Cultural/Linguistic-Specific Family Support Centers are designed to respond to the unique needs of specific cultural and linguistic family groups in specified areas of the State. English is not the primary language for many of these families, and as a result they face linguistic barriers in accessing services and require more individualized and specialized assistance to learn about and access the service system. These Centers offer a similar array of services as the Family Support Centers described above. There are ten Cultural/Linguistic-Specific Family Support Centers with funding totaling approximately \$980,000 dollars.

Autism Support Centers provide an array of information and referral services, resources, and supports to children with autism spectrum disorders (ASD) and their families, and in the past two years has expanded their focus to support adults with ASD and Developmental Disabilities and their families who are part of the newly eligible population. The array of services and supports includes, but is not limited to, information and referral, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events. Continued exploration and understanding of ways to best engage the new expansion population of adults with ASD is an area of focus for continued development.

Most of these adults live at home with their family and are competent (do not have a legal guardian). It has been challenging to engage some of these adults in using services that may be appropriate and beneficial to them, while also supporting their families who may be interested in having their son/daughter access specific services and supports. There are five large and two smaller regional autism support centers funded at approximately \$2.8 million dollars, which covers the community based initiatives and other center activities outside the Autism Waiver Program. They typically reach thousands of families a year with information and resources, and also offer a diverse array of center and community-based activities that many individuals and families participate in throughout the year.

Intensive Flexible Family Supports (IFFS) Programs are designed to help families who are experiencing severe stress which can lead to the child being at risk of an out-of-home placement. Intensive case management services are provided to help families access and integrate the variety of available resources to support their family member in crisis, and flexible funding to purchase additional supports or goods. These program services, originally designed to assist families of children between the ages of 3 and 18, have been expanded to age 22 to be responsive to the emerging needs of the 18 to 22 age group of young adults living with their families. Annually, about 685 children and their families receive services through the 20 regional and area based programs across the State, funded at approximately \$2.5 million dollars.

Medically Complex Programs support families who are caring for children/young adults up to the age of 25, with significant cognitive, physical, and complex health care needs who are living

at home. Intensive medical wrap-around case management services are provided to help families integrate the variety of resources and supports they are receiving and offer flexible funding/stipends to assist the family in the purchase of additional supports and goods not covered by health insurance. This program complements and is supplemental to other MassHealth State plan and third-party insurers. Annually, these programs provide services to about 400 to 425 individuals and their families. These five regionally based programs are funded in total at approximately \$710,000.

There is currently one **Planned Facility Based Respite Program for Children** that offers planned, out-of-home respite services for children in the Central/West Region. This program provides short-term temporary relief for families, and include overnight, weekend, and/or vacation stays. Individuals are provided with a variety of recreational, social, cultural and/or educational activities during their stay. On average, about 60 children and their families are able to utilize this service on multiple occasions across the year, with a total funding amount of approximately \$226,000.

In addition, the Department operates the **Medical Respite Home** in Southeastern, MA that provides an important resource for adults with complex medical, physical and developmental needs who require 24 hour, specialized nursing care, and their families. First opened in 2012 in response to the need identified by families for this out-of-home respite option, this program has continued to evolve, and includes transportation, a variety of community-based activities, and other supports to assist individuals and families to successfully utilize this option. Approximately 41 individuals and their families have been able to use this resource for a total of 853 overnight stays, providing important relief and respite for families and a new experience for the adults. This continues to be a valuable and helpful resource for families statewide.

Family Leadership Development Programs provide education, mentoring and support to families. A major focus is a comprehensive and intensive family leadership series which provides information and education about “best practices” and helps families gain knowledge about policy making at the local and state level to assist them in assuming leadership roles in their local community and the disability community. They also provide a workshop series, “A Full Life Ahead” in each region as well as other conferences and workshops promoting the knowledge base and leadership potential of families to help enable their family member to lead a full and meaningful life in the community. There are five regionally based Family Leadership Programs funded for a total of approximately \$400,000.

The Autism Division at DDS received \$5.6 million dollars in FY 2017 to provide services and supports to children with autism. The Medicaid Home and Community-Based Services Children’s Autism Waiver Program serves about 260 children under the age of 9 at any one point in time. The Autism Division also helps fund a specialty community program designed to train first responders called the Autism and Law Enforcement Education Coalition (ALEC). This program remains a successful initiative which has received national recognition.

The Department of Elementary and Secondary Education & Department of Developmental Services Community Residential Education Program (DESE/DDS) is a successful collaborative initiative designed to provide supplemental supports to children/young adults determined to need services to prevent a more restrictive educational or out of home residential placement, or to assist families whose children are coming out of a residential placement. The intent of the program is to increase family capacity to support their child in the home and community, as well as to provide an individualized plan of supports that promotes skill building, independence, and social integration across the spectrum of the child’s home, school and

community. In FY 2017, the program continued to receive \$6.5 million to provide capacity building supports and related services to about 500 participants across the year ranging in age from 8 up to 22. Twenty individuals transitioned out of the Program because they turned 22. An Open Interest period was held in the winter of 2017 to provide families the opportunity to express their interest in being considered for enrollment in the DESE/DDS program through completion of an application. This resulted in the submission of 649 requests. Verification of DDS eligibility is reviewed and children and their families will go through an assessment process as resources in the program become available.

Outcomes with FY 2017 Family Support Expansion Funding

These are major highlights and accomplishments DDS was able to implement this past fiscal year with the expansion funding of \$5 million dollars for family support services. These priority areas were established with consultative input from the Family Support Council and other stakeholders.

- 1) Additional supports and resources were provided to older parents/caregivers who are continuing to provide care for their family member at home. Outreach and support was offered to about 600 older parents/caregivers, many of whom are caring for an adult son or daughter over the age of 60. About 500 older caregivers were provided in-home and community support services and/or flexible funding allocations. In addition, some of these older caregivers were connected to other elder-service agency resources and many Family Support Centers provided new or expanded support groups and other resources for these caregivers.
- 2) About 2,000 families were provided individual flexible funding/stipend allocations, which continues to be one of the most important and beneficial services identified by families. About 75% of this funding was provided to families in need who had not been receiving any individualized funding support, and about 25% to families with an existing allocation to provide increased resources to help them care for their family member at home.
- 3) Capacity was increased in some areas to serve more families through the Intensive Flexible Family Support Services programs, and additional staffing resources was added to some selected local Family Support and/or Cultural/linguistic-Specific Centers where there was a specific need to build additional capacity.
- 4) Funding for 18 innovation grants were awarded to foster and promote social capital and community membership and inclusion that will benefit children and adults living at home with their families. This is an exciting new initiative that is intended to serve as a catalyst to seed opportunities that will expand over time to integrate opportunities for meaningful inclusion and community participation in all aspects of community life.

DDS reviews progress on new initiatives and funding priorities throughout the fiscal year and provides periodic reports to the Family Support Council, the Statewide Advisory Council, and other interested stakeholders.

IV. Accessing Services and Supports

What are current examples of ways the agency is educating families on how to access services in a timely and effective manner? What are some illustrations of different services and resources which promote good access to information and referral?

The DDS funded Family Support, Cultural/Linguistic-Specific, and Autism Support Centers provide Information and Referral services to families of children and adults within their geographic area. This includes assisting families to identify resources and service options available in their local communities, to learn about other financial and/or state services for which families may be eligible, and to provide guidance on how to navigate the service system. They

use a variety of approaches to disseminate information to families, including email, list-serves, web-sites, on-line newsletters and training calendars, webinars, and social media, as well as create and maintain a “library” of resources. These Centers engage in a variety of outreach activities to connect with families in different venues who may benefit from their information and resource services, including early intervention programs, local school systems, health care providers and through other community based organizations.

When individuals are found eligible for DDS services, families are sent a ‘welcome flier’ with information about the Family and Autism Support Centers, which encourages families who are not already connected to a local Center the information they need to make that contact. This notice is made available in multiple languages to be responsive to families for whom English is not their primary language.

A ‘Statewide Family Support Directory’ is available to help families find the Family Support and Autism Support Center and other family support programs in their area to promote easier access to these resources. The Directory is widely disseminated through DDS, service providers, and is posted on the DDS website.

DDS has provided funding for a project called “Widening the Circle” with the Arc of Massachusetts to assist in expanding opportunities for friendships between individuals with and without disabilities and community participation through training and the development and distribution of information and resources. A website with resource information has been developed, and staff have delivered over 125 “Introduction to Friends” presentations across the state reaching about 3,000 people including parents, people with disabilities, and DDS and provider staff, and have also conducted ‘train the trainer’ sessions. This past year a new toolkit to help foster friendships at school was developed entitled, “Making Friends in School” and is available at: <http://thearcofmass.org/toolkit/>

DDS sponsored multiple statewide training events over the past year for family support providers and DDS staff, all designed to build expertise and knowledge to enhance the quality of supports and services provided to families across the life span. These events provide opportunities for staff to share information, promising practices, and new initiatives in specific topical areas, and foster an opportunity for networking. About 500 staff participated in these different training events. To support the Department’s initiative to outreach to and better support older caregivers, a training was held that included presentations by staff from the Executive Office of Elder Services about their array of services, complemented by presentations on successful local partnerships between elder service agencies and family support providers to engage and support older caregivers. A *Showcase on Social Inclusion* featured presentations by a diverse array of parents who have developed interesting initiatives to support meaningful inclusion and participation in different aspects of community life for their child or adult with a disability. This showcase was intended to support momentum generated at the annual family support conference in May 2016 focused on the topic of social capital and community inclusion. These presentations by parents were inspiring and empowering, and helped spark ideas about what is possible and what steps can be taken to help foster and support community membership.

A successful statewide conference, “Building Bridges to Inclusive Communities,” was held in May 2017 and built off the successful conference held last year with a similar thematic focus. Al Condeluci from the University of Pittsburgh School of Social Work and School of Health and Rehabilitative Services, once again was the keynote speaker and provided an in-depth presentation on effective approaches, tools and resources to assist individuals in developing

meaningful relationships and build community connections. Break-out sessions offered great opportunities to share experiences and insights on successful bridge-building and development of meaningful community membership in different aspects of community life, ranging from recreation, to fostering friendships at school, to spiritual life. Family members participated in many of these sessions and offered helpful experiences and perspectives on how they successfully created meaningful membership in the community for their sons and daughters. A resource guide was developed and disseminated which provided a listing of different resources for further information in the area of social and community inclusion.

Other ways DDS helps make services accessible to families is through funding support for New England INDEX, and specifically the Autism Insurance Resource Center which provides information, training and consultation about the Massachusetts Autism Insurance Law (aka ARICA). DDS helps disseminate information about this resource to families and staff through multiple strategies. In addition, a variety of publications and informational materials are posted on the DDS web-site to help families learn more about services and how to access them.

What new initiative(s) will the agency undertake to promote good local access to information and resources?

- The DDS Regional Intake and Eligibility teams engage in outreach and provide training to varied groups and organizations about the DDS eligibility criteria and process to help reach families who may need this information.
- Sessions for families called “Ask the Agency” will continue to be hosted by some area offices and regions in partnership with their local Family Support Center. These sessions provide an overview of eligibility, the array of available services, self-directed service options, and specific services for adults with Autism Spectrum Disorder, with a chance to address specific questions family members may have. These informational sessions are well-received and will continue to be offered in different places along with other outreach efforts.
- DDS will be exploring ways to develop more in-depth understanding of the different “Charting the Life Course” guides that have been developed by the Missouri Family to Family Center, and explore ways to integrate these tools in our family support planning and services with families.
- Forums on Turning 22, the transition process from school to adult services, will continue to be sponsored for families by all DDS Area offices in partnership with local Family Support Centers and/or other providers to help families understand the process and learn about adult service options and service providers. A set of fact sheets on key topics related to planning for the transition from school to adult life are available to families in these sessions and on our web-site. “*Important Transition Information Every Family Should Know*” is a set of 26 fact sheets available to families and can be used in a flexible way to help families build their knowledge and resources about all aspects of this transition process. These fact sheets are translated and available in Spanish. Presentations on the topic of supporting families through the transition planning process are also given at several large statewide conferences for families, including the Federation for Children with Special Needs and the Massachusetts Down Syndrome Congress.
- DDS continues to fund and support the web-based Rewarding Work Respite Directory that provides a listing of workers and other resources related to accessing respite and hiring in-home support staff. Individuals and families who receive services through DDS

can access this directory at no cost. A new automated job posting function feature has been developed that allows individuals and families to recruit workers in a way that is more customized and specific to their unique needs. It's expected this will be an easier and more successful approach for finding workers more efficiently that are a good match for the individual/family situation. This initiative was developed in response to the concerns raised by families about the difficulty in finding respite workers. The focus in this upcoming year will be on strategic outreach to recruit potential workers and to spread the word to reach families about this resource. Additionally, several small pilot respite training projects will continue to be explored and implemented to help expand the pool of respite workers and options for families.

- DDS along with all other state agencies is re-designing our agency web-site with the goal of making the site easier to navigate and information more readily accessible.

V. Culturally Competent Outreach & Support

What are the current activities or services that the agency offers that ensure culturally appropriate access and supports to ethnically, culturally, and linguistically diverse families and individuals?

The Cultural/Linguistic-Specific Family Support Centers provide bi-lingual and bi-cultural assistance to identified groups of families for whom English is not their primary language. They provide broad outreach and are frequently called upon by other organizations to help provide interpretation and translation assistance to families. These Centers primarily provide services to families who speak Spanish, Chinese, Vietnamese, Khmer, Russian, Haitian Creole, Portuguese, and Cape Verdean Creole. In addition, all Family Support Centers and providers are expected to develop resources and capacity to do outreach and be responsive to the diverse cultural and linguistic communities in the geographic area in which they are providing services.

There are an increasing number of children and families from a variety of diverse cultural and linguistic communities who receive services through the Autism Waiver Program. Interpretation services are provided as an integral part of these in-home program services.

DDS makes available translated informational materials for individuals and families in multiple languages. Positive working relationships have been established with several entities that provide interpretation and translation services and they have developed a good understanding of disability terminology and concepts that lead to providing more culturally relevant and responsive information. DDS updated our Language Access Plan and this past year initiated a new telephonic interpreter service that provides for real-time, on demand interpretation in many languages by someone who is contacting the Department by telephone. This resource has improved access to communication between DDS Service Coordinators and staff with individuals and family members on their caseload for whom English is not their first language.

DDS will continue to offer training opportunities for family support and DDS staff focused on increased understanding of families from diverse communities and to learn more about resources and strategies to provide culturally respectful and responsive services. It's important to foster learning from staff at the Cultural/Linguistic-Specific Centers and provide opportunities to hear directly from families from diverse communities about their experiences and perspectives in raising a child with a disability, and from providers about the approaches they have developed and used to offer culturally responsive services. Through regional meetings DDS staff continue to work collaboratively with providers to share positive practices and support

them as they further develop their capacity to provide services to individuals and families from diverse communities.

There are active statewide, regional and central office Diversity Councils that offer a variety of opportunities for education, training, and cultural experiences to promote increased understanding of different cultural and linguistic groups, and support the delivery of more culturally responsive services.

What new ideas/initiatives will the agency propose to outreach and meet the needs of culturally diverse families and individuals?

- Workshops and forums focused on the development of culturally responsive services will continue to be provided for Family Support providers and DDS staff, with an emphasis on creating a welcoming environment to help families access services. Opportunities will be fostered to share strategies, resources and local partnerships that have been effective.
- Training on language access and use of interpreters has been integrated into the orientation required for all DDS employees and provider staff.

VI. Interagency Collaboration

Department staff participate in various inter-agency activities with other Executive Office of Health and Human Services (EOHHS) agencies to promote more effective service delivery and to maximize resources. Regional and area office DDS staff participate in local inter-agency planning teams to promote more effective communication, and when there are individuals involved with multiple agencies, to work toward coordination and collaboration in service delivery. Representation on these teams usually includes staff from the Departments of Children and Families, Mental Health, Transitional Assistance and Public Health, and in some situations, representatives from local school systems.

DDS, in partnership with the Executive Office of Elder Affairs, other human service agencies and community organizations, has completed the seventh year of a federal *Lifespan Respite Grant* from the Administration on Aging. A unique aspect of this project has been the cross-disability/special needs focus across the lifespan. A statewide lifespan respite coalition has been established, a website with respite resources and information on varied respite options has been developed, and training approaches and innovative models to expand the network of respite providers available to caregivers continue to be identified, with the goal of helping to address the well documented and essential need for respite for caregivers providing daily assistance and care for family members with disabilities. This past year ten mini-grant demonstration projects were funded to support the delivery of respite services to unserved and underserved populations. DDS, in partnership with Elder Services, DPH, DMH, the Lifespan Respite Coalition and the Health Education Center at UMass Medical School have submitted a new federal lifespan respite grant. If successful, this proposal will have a strong focus on training to increase the pool of qualified workers to provide respite, and inter-agency planning and coordination across state agencies to work strategically to identify and track funding and outcomes, best practices, and approaches to build synergy and improve access to resources.

DDS staff continue to collaborate with staff from Elder Services, including the Aging and Disability Resource Centers (ADRC), and the aging network across the state to better understand the needs and resources to support the aging population of individuals served by DDS which has significantly increased in recent years, as well as strategies to make services

more accessible and responsive. Joint trainings and service initiatives have been developed, including continued funding for thirteen Memory Cafes across the state to provide enriching experiences and support to older individuals experiencing memory loss and their caregivers. This partnership is an important way to focus on ongoing efforts to provide more instrumental support and resources to older family members who are continuing to be the primary caregiver for their adult son/daughter at home with an intellectual disability.

DDS leadership staff continue to be active members of the Autism Commission and have been working in partnership with other state agencies, advocacy groups and other stakeholders to support implementation of key recommendations identified in the 2013 report and the provisions of the Autism Omnibus Act of 2014. Multiple DDS staff at all levels of the organization are active members of the varied workgroups established to address the goals and need areas outlined in the Commission report. A strong inter-agency partnership has developed with the Department of Mental Health to better support adults with Autism Spectrum Disorder and Developmental Disability, many of whom are living with their families and experience co-occurring mental health issues.

DDS continues to work collaboratively with the Office of Medicaid, and the Departments of Mental Health and Children and Families, on the implementation of the Children's Behavioral Health Initiative (CBHI). An area of ongoing attention and focus has been to identify approaches so these services are more tailored and responsive to the needs of children with autism spectrum disorders, including training needs and opportunities to support capacity building in this area. DDS works with partners to offer training and make information available for agency staff and family support providers so they are knowledgeable about the eligibility criteria and service options available in order to facilitate access to these services for children and families who may be eligible. DDS has also worked closely with MassHealth to share information on the Applied Behavioral Analysis (ABA) service that is now available through the State plan to help facilitate access to this service for children who are eligible and can benefit from this service

Department staff participate in Unified Planning Team meetings when requested for individuals who are eligible for DDS services, consult to EOHHS Unified Planning Teams for children who are not eligible for DDS services, and also continue to participate on the *One Child, One Plan* EOHHS initiative. DDS family support staff and children and transition service coordinators are collaborating with the Department of Public Health Care Coordination Program to help facilitate planning and smoother transition from school to adult life for individuals with significant and complex medical, physical, and developmental needs.

What new activities or initiatives does the agency propose to demonstrate the above goals?

- DDS received a five year federal grant from the Administration on Intellectual and Developmental Disabilities, the Massachusetts Partnership for Transition to Employment (MPTE). This is a system change project focused on improving career development and employment experiences for students and young adults with Intellectual and Developmental Disabilities to facilitate movement into integrated competitive employment and/or post-secondary options upon leaving school. Specific areas of focus include family engagement, promotion of self-determination and self-advocacy, and cross-system collaboration and coordination. Key partner agencies include the Department of Elementary and Secondary Education (DESE), the Massachusetts Rehabilitation Commission, and the Department of Labor Workforce Development complemented by diverse representation of family advocacy groups, self-advocates, local school system representatives, employment provider agencies, and other stakeholders.

- DDS staff will continue to work closely with the Executive Office of Elder Services on a variety of initiatives focused on supports for older caregivers, services and resources for individuals with ID who are aging, and in implementation of the Memory Café's. This will include planning of joint training sessions, sharing of resources, and development of local partnerships. DDS will also continue to collaborate with Elder Services and other human service and community organizations, family members and individuals to successfully implement the federal Lifespan Respite grant, support the Massachusetts Lifespan Respite Coalition, and promote use of the Rewarding Work Respite Directory.
- DDS and DMH will continue to develop and implement joint agency plans to better support adults with ASD who also experience other mental health challenges.
- DDS is participating in a renewed state agency collaborative effort with The Commission on the Status of Grandparents Raising Grandchildren.
- Leadership staff at MassHealth and DDS continue to work together to develop strategies to respond to several need areas identified by families that will better address the health care and support needs of individuals with significant medical and physical challenges, such as approval and processing time for durable medical equipment and quality of diapers and other absorbent products. This past year a training was arranged by MassHealth for DDS staff and the DDS funded Medically Complex Programs to provide updated information on the Community Case Management Program that provides services to children and adults receiving continuous skilled nursing care at home.
- DDS will continue to work in partnership with the Office of Medicaid in the implementation of the Home and Community Based Waiver Programs for adults and the Autism Waiver Program for Children.