**Charles D. Baker**
Governor

**Karyn Polito**
Lieutenant Governor

**Marylou Sudders**
Secretary

**Jane F. Ryder**
Commissioner

# Department of Developmental Services

# Chapter 171 Report and Annual Individual and Family Support Plan

## Fiscal Year 2021

## February 2021

Massachusetts Department of Developmental Services

# Department of Developmental Services
# Annual Family Support Plan
# Fiscal Year 2021 (FY21)

## 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 eighteenth 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 contributing members in their 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 their home. The Family Support Centers and other support programs are designed to be responsive to the dynamic and changing needs of the individual with a disability and their 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 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. In FY 2020 the budget appropriation was $70,752,883, which reflected an increase of $3.2 million from FY 2019. Of this total appropriation, approximately $60 million is for specific family support services, and the remainder for other community support services. With this expansion funding, DDS was able to provide direct assistance to approximately 1,200 families who had not been receiving individualized services, or for families who needed additional supports to assist them in their caregiving role. These resources were used for respite, flexible funding allocations, and other in-home and community supports. The array of family support services provided is described in more detail in Section III, Family Support Resources and Funding.

The onset of the COVID-19 pandemic and public health emergency in March 2020 has had a significant impact on all citizens across the Commonwealth, including families caring for a loved one with an intellectual/developmental disability at home. State agencies and service providers quickly responded to this crisis, both in addressing emergency needs and the way services and supports are delivered – namely, moving to virtual and remote approaches. DDS' Flexible Funding Guidance was modified to provide more flexibility in how these funding allocations (administered by Family Support Programs) could be used to support families during this difficult period. For example, allowing funding resources to be used for short-term basic emergency needs such as food insecurity, household items including disinfectants, adaptive equipment or technology devices to create increased access, and supplies for enrichment and leisure.

Family Support Programs have been very proactive in their outreach to families since the public health emergency declaration in March, maintaining regular contact to provide timely information and resources related to the pandemic and for overall support. Providers developed a variety of virtual and remote programming opportunities beneficial to both individuals and caregivers, including support groups, classes, trainings, music therapy, stress management, among others. This array of supportive services has provided an important lifeline to families. There has been great collaboration among providers, resulting in the sharing of resources, increased access to opportunities, and networking - minimizing the barriers that sometimes occur due to geography and transportation challenges. DDS is tracking this information and evaluating overall impact to identify potential long-term changes that should be integrated into services moving forward.

As of June 2020, there are currently about 42,300 individuals eligible for DDS services living in the community – and approximately 22,000 live with their families. This breaks out in the following way:

- Approximately 9,500 children under the age of 18;
- Approximately 4,850 individuals between the ages of 18 and 22; and
- 27,945 adults over the age of 22.

Eligibility for DDS adult services was expanded to include adults with Autism Spectrum Disorders (ASD), Prader-Willi Syndrome, and Smith-Magenis Syndrome, as a result of the Autism Omnibus Act passed in 2014. 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 (substantial functional impairments in three or more of seven life areas). As of June 2020, there are approximately 2,535 individuals with ASD who have been found eligible for adult services, and 10 individuals with Prader-Willi Syndrome. Of the total number of individuals with ASD, approximately 960 (38%) are between the ages of 18 through 21, and 1,570 (62%) are age 22 and older.

There is a DDS Autism Service Coordinator in each Area office who specializes in working with adults with ASD. 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, individual supports for people who are living more independently, and coaching services. DDS always strives to better engage adults with ASD to use the services that are available, and DDS continues to explore new service models and approaches to meet their diverse array of needs. A positive trend is that more of these adults choose to self-direct their services through the Participant-Directed Program or Agency With Choice models, which enables them to tailor and customize their services the way they view as most helpful.

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

DDS seeks input and guidance from individuals with intellectual disabilities and their families through multiple formal and informal approaches to help assess the Department's current system of family support services and inform areas for development. Through consultation and in partnership with family members, providers, and other stakeholders, the most important needs identified by families include respite, access to flexible funding/stipend resources, increased options for social and recreational experiences, access to information, and help navigating services. These priorities have provided a framework for the services we work to make available through our family support services. More information is available in the report *In Their Own Words: The Need for Family Support Services*, which also highlights the benefits and cost-effectiveness of family support services. Family Support services are found to be 75% to 80% less expensive than providing services to an individual in an out-of-home residential placement. This report is available on the DDS website.

The **Statewide Family Support Council** is a vehicle to provide substantive and ongoing input and consultation to the Commissioner and other leadership staff related to family support services, practices, policies, and needs. This group is comprised of parents from across the state who have, or recently had children and adult family members with disabilities living at home. Council members have played integral roles in family support strategic planning processes, provided input the procurement of family support services, and continue to have an important role in assisting DDS in the implementation of specific initiatives 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 23 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.

The Commissioner along with other leadership staff meet on a regular basis 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 released in March 2013, and the plan that is updated annually.

During the fall of 2019, DDS worked on the development of a new procurement for our Family Support Services that was posted in early 2020. This procurement includes the Family, Cultural/Linguistic, and Autism Support Centers, Intensive Flexible Family Support, Medically Complex and the Family Leadership Programs. This planning provided an opportunity to seek input from family members and providers to help inform ideas, changes, and priority areas to consider in this development process. Two sessions were held with current providers of family support services, and six forums for family members were held across the state, in addition to an on-line survey that was developed and translated into multiple languages, which was completed by more than 500 families. The following are some of the highlights and key themes that emerged:

- Supports described as most helpful included; flexibility of services, relationship building with families to understand their wants and needs; help with navigating services and connections to a myriad of other resources; opportunities to connect with other families with shared life experiences; and the wide array of social, recreational, and community activities for individuals and families, though this may vary by provider and geography.

- Some of the most important service needs identified include: respite, flexible funding, linguistic access; help with transition planning, support with guardianship or other alternatives, help with finding staff for respite or community supports, and more individualized support to enable individuals with more complex medical or behavioral support needs to participate in social and recreational opportunities.
- Areas identified as needing further development included: improved outreach and communication so families know what services and resources are available to them, and assistance to make connections with local Family Support programs; more local geographic access to services and opportunities offered by family support programs along with knowledge of local community resources; regular communication, using multiple approaches in order to be responsive to the preferred modes of families; additional assistance with planning at key life transition points, especially from school to adult services; increased supports for siblings as well as mentors and support groups for parents- highlighting the benefits of networking; and, language access-services to be provided in preferred language of families

This feedback helped inform some key elements and changes that were integrated into the Family Support procurement.

**Highlights from FY 2020:**

- With expansion funding of over $3 million dollars in FY 2020, DDS was able to expand service capacity in existing family support programs and provide direct assistance to approximately 1200 families caring for a family member at home though individual flexible funding allocations. These funding resources were also instrumental in the response to the COVID-19 pandemic to help address emergency and other basic support needs of families.
- DDS developed and issued a new procurement for the array of Family Support Services programs we provide, which includes the Support Centers (Family, Cultural/Linguistic, Autism), Intensive Flexible Family Support, Medically Complex and the Family Leadership Programs. This Request for Response (RFR) was originally issued in February 2020, but due to the COVID-19 pandemic was taken down given DDS staff and providers were immersed in responding to this public health emergency. The RFR was reissued in late August 2020. Contract awards were made in December 2020 for 80 Family Support programs, with new contracts in place for a January 1, 2021 start date.
- DDS, in partnership with the Massachusetts Developmental Disabilities Council, began participation in a national Community of Practice in Supporting Families hosted by the University of Missouri/Kansas City and the National Association of State Directors of Developmental Disability Services (NASDDDS). The goal of this three-year initiative is to build capacity, though a community of practice, across and within states, to create policies, practices, and systems to better assist and support families across the lifespan that include a member with an intellectual and developmental disability.
- DDS continues to provide training and related learning opportunities on *Charting the LifeCourse*, a framework and set of principles, tools and resources that help individuals and families plan for a full life based on the belief that all people have the right to live, love, work, play, and pursue their life aspirations in the community. DDS works in partnership with staff at the University of Missouri/ Kansas City who developed this, along with other stakeholders, to support integration of these practices in our work with individuals and families.

## D. Focus Areas: Review of Activities and Accomplishments in FY 2020 and Proposed Initiatives for FY 2021

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?*

As previously referenced, 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. The statewide Self-Determination Advisory Board established to support implementation of the Real Lives legislation in 2014 includes adults who are actively engaged in self-directing their services as well as family members. Their input and experiences help inform the evolution of these self-directed service options, Agency With Choice and the Participant-Directed Program, and identify ways to help educate and inform others about the benefits of these opportunities.

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, such as *Employment First, Positive Behavioral Supports, Shared Living, and Technology Forward*, 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 their unique needs, strengths and cultural values.

- ❖ Family Support Council members provided important and helpful input in the development of the new *Family Support Program Manual and Guidelines* issued in January 2019 as well as the new procurement for Family Support Services. Flexible funding resources provide families with choice and flexibility about the types of assistance that will be of greatest benefit to them in their caregiving role. A small group of Council members continue to work closely with DDS staff to seek input in the development of a companion manual, "Supporting Families: A Guide for Family Support Services." Specific attention is being paid on providing information so it can be more accessible to families from different cultural and linguistic communities.
- ❖ The regional Self-Direction Managers engage in regular outreach to individuals and families and host forums with a variety of partners including Family Support and Autism Support Centers, to provide information about the self-directed service options available through DDS. Individuals and families who participate in either the *Agency With Choice (AWC)* model or the Participant-Directed Program (PDP) are empowered through the choice and control they have in designing and planning services and selecting staff. They also play an important role in sharing their stories and experiences, to help educate others about the opportunities to engage in self-direction - a powerful way to exercise empowerment. DDS has established funding resources and a consistent process for compensating individual and family presenters which has been an important way to expand the pool of speakers.

- As of June 2020, there are about 588 individuals/families using the Agency With Choice model, and about 882 individuals/families engaged in self-direction through the Participant-Directed Program. There is a higher percentage of adults with ASD who are choosing one of these self-direction service approaches due to the flexibility in tailoring services to best meet their needs.
- 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 that will provide supports.
- The DDS Adult Home and Community Based Waiver Programs provide opportunities for individual and family empowerment through choice in service delivery approaches, service providers, and portability of services.

## 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. An important aspect of these programs is that the training and mentoring is developed and provided by families who have a family member with a disability. The cornerstone of these programs is the *Family Leadership Series,* which occurs across 6-8 days over a several month period. In planning these trainings there have been concerted efforts to attract and support families from different cultural and linguistic communities. Many graduates of this series move into new leadership roles in a variety of capacities and play active and effective roles in helping shape policy and services. A variety of other training opportunities are offered, including an Advocacy Bootcamp for younger families and a training series called “A Full Life Ahead” that offers topical seminars for families in a variety of areas including sexuality, self-direction, person-centered planning, transition, housing, alternatives to guardianship, employment, futures planning, and fostering friendships. Hundreds of families are reached through these trainings annually across the state.

Additionally, the DDS funded Family Support and Autism Support Centers provide an array of educational events and training opportunities for families of both children and adults on relevant topics of interest that enhance both their knowledge as well as their leadership skills. These Centers are required to offer a minimum of six training events per year, with many offering additional training opportunities. This type of opportunity fosters the development of leadership skills among parents. 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?*

Families and individuals with disabilities exercise their leadership skills as members of the DDS Statewide Advisory School and 23 Citizen Advisory Boards, through participation in the DDS-funded Family Leadership Projects, as well as through Advisory Councils with the Family and Autism Support Centers which are expected to actively engage families to seek consultation to identify their interests and needs in developing programming and array of service options to be offered.

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 them to expand their own repertoire of 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 designed 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. Center staff 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. Additionally, Service Navigation is offered to provide 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 resources to families who are prioritized to receive an individual allocation which can be used by families to purchase allowable services and goods as defined in the Department's 2019 Family Support Program Manual and Guidelines. There are 34 Centers funded across the State with funding totaling approximately $13.3 million. These Centers along with the Cultural/Linguistic Specific Centers described below provide some type of individualized assistance to about 13,000 families a year, plus reach many more through information and referral, trainings and recreational and community events. These Centers also administered almost $10 million 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 and related supports. These Centers offer a similar array of services as the Family Support Centers described above. There are 10 Cultural/Linguistic-Specific Family Support Centers with funding totaling approximately $1.4 million.

**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 over the past five years have expanded their focus to include a growing number of adults with ASD and Developmental Disabilities and their families. The array of services and supports include information and referral, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events. Center staff continue to explore and develop different opportunities and ways to engage adults with ASD in activities and support services, while also providing assistance to their families. There are five large and two smaller regional autism support centers funded at almost $3 million. This funding covers the community-based initiatives and other center activities outside of the Autism Waiver Program. The Centers typically reach thousands of families a year with information and resources, and 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 their child/young adult 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 are designed to assist families of children between the ages of 3 and 22. Annually, about 650 children and their families receive services through the 20 regional and area-based programs across the State, funded at approximately $2.9 million.

**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 $740,000.

The Department also operates a **Medical Respite Home** in Southeastern, MA that provides an important resource for families of adults with complex medical, physical and developmental needs who require 24-hour, specialized nursing care. 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 66 individuals have completed the intake process for the respite home, and 42 individuals and their families used this resource for a total of 385 overnight stays during FY20. It should be noted that as of March 13, 2020 the respite home needed to discontinue providing these services due to the emerging COVID-19 pandemic. This accounts for the decrease in reported overnight stays from those in 2019 (591). These services provide important relief and respite for families and an enriching and social experience for the adults. This continues to be a valuable and helpful resource for families statewide and is expected to become available again once this public health emergency has ended.

**Family Leadership Development Programs** provide education, mentoring and support to families. A comprehensive and intensive family leadership series is offered 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 $475,000.

**The Autism Division** at DDS is funded at about $6.9 million to provide services and supports to eligible children with autism through the Medicaid Home and Community-Based Services Children's Autism Waiver Program. This program serves about 280 children under the age of 9 at any one point in time, and 380 children across the year. An open interest period is held annually to provide an opportunity for families to identify their interest in having their child be considered for this program. This Waiver Program is up for renewal for another 5 years beginning on 10/1/2020 which will increase the number of children served to 300 at any one point in time, and 400 children across the waiver year during the first year of this renewal. 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 returning from 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 FY20, DDS received $10.5 million to expand the program, an increase of $4 million. With this expansion funding 282 new participants started the program during the fiscal year, for an overall total of 782 youth and their families participating in the program. The Department launched an Open Interest period in the fall of 2019 which ran through February 2020 – and over 600 interest forms were received. The Open Interest Form was translated into eight languages and there was broad outreach. The Department hired six new staff to support the growth of the program. The positions include a Statewide Program Manager, an Educational Specialist, and four Program Coordinators who work in each of the four regional offices. The DESE/DDS program has 47 qualified providers and added eight new agencies since the last RFR.

In March the program pivoted to meet the extraordinary and more immediate needs of families who found themselves and their children at home full time due to the pandemic. The Department created more flexibility in the use of the DESE/DDS funding and permitted the resources to be used for assistance with short-term emergency needs such as food insecurity, resources to purchase household items including disinfectant wipes, bleach, etc., and allowed the funding to be used for adaptive equipment, technology devices, supplies for recreation and leisure, and sensory items. Families were also able to use resources for child care beyond the program's typical limits.

DDS reviews progress on 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 with applying for eligibility for DDS services, as well as identifying resources and service options available in their local communities. Center staff assist families to learn about and access other financial and/or state services for which families may be eligible, and 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. 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 help ensure access.

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, as well as other related resources to promote easier access. The Directory is widely disseminated through DDS, service providers, and is posted on the DDS website. During this past year, DDS updated and reorganized the agency website to make information for individuals and families easier to access. In addition, the Department has expanded use of social media to provide information, resources, and updates in a timely way and through approaches individuals and families more typically use.

DDS continues to provide funding for "Widening the Circle" a project with the Arc of Massachusetts to assist in expanding opportunities for meaningful community membership and the development of friendships between individuals with and without disabilities. The project provides training for staff, families and individuals with disabilities, and offers a train-the-trainer series, as well as consultation and mentoring to other provider agencies on ways to foster community membership and friendships. They have a website with resources which includes several toolkits that have been developed, with the most recent one focused on strategies to foster friendships where you live entitled, "Making Friends in the Community: Where You Play, Serve, and Worship." These toolkits are available online at: http://thearcofmass.org/toolkit/.

DDS continues to provide opportunities for staff and families to become exposed to and learn more about the Charting the LifeCourse framework and tools that provide person-and family-centered resources to help with planning and problem-solving. Through training, workshops and monthly 'Tools in Action' calls, there are opportunities to share information, promising practices, and experiences. This past year DDS became involved in a three-year national Community of Practice on supporting families across the lifespan sponsored by the University of Missouri/Kansas City and the National Association of State Directors of Developmental Disability Services (NASDDDS). This is an exciting initiative that will enhance ways supports are offered to individuals and families at all life stages, and will involve other state agency partners and stakeholders.

Following a Roundtable on supporting parents living with Intellectual and Developmental Disabilities (ID/DD) in March 2019, DDS has been engaged with other state agency partners and community providers on some key initiatives. This Roundtable provided an opportunity to learn more about the current needs of parents, services and resources that are available, to identify gaps and challenges, and to determine next steps in order to enhance the supports available to these parents, and the providers and staff who are working to assist them. A Resource Directory is under development and several training opportunities were offered to share information about effective service delivery approaches and resources to support individuals in their parenting role. Additional initiatives will be undertaken in the upcoming year to foster increased understanding of best practices, address gaps and build capacity among providers, professionals, and families.

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. DDS also offers many presentations on DDS services and the eligibility process for families and other professionals, and host resource tables at other statewide conferences for families such as the annual conference sponsored by the Federation for Children with Special Needs, and the transition conference sponsored by The Arc of Massachusetts, among others.

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

- The DDS Regional Intake and Eligibility teams will continue to 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" or "DDS 101" will continue to be hosted by some area offices and regions in partnership with their local Family Support Centers. 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.
- 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.
- DDS continues to provide funding 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. Through an automated job posting function, individuals and families can identify their needs and recruit workers in a way that is more customized and specific to their unique needs. This initiative was developed in response to the concerns raised by families about the difficulty in finding respite and in-home workers. Through this initiative there are strategic outreach efforts to recruit potential workers, such as on college campuses and at job fairs, and to spread the word to reach a broad group of families about this free resource.

## V. <u>Culturally Competent Outreach & Support</u>

*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 and translation services are provided as an integral part of these in-home program services.

DDS makes available interpreter services and translated informational materials for individuals and families in multiple languages. Effective working relationships have been established with several interpretation and translation services organizations and they have developed a good understanding of disability terminology and concepts that lead to providing more culturally relevant and responsive information. In addition, DDS has a telephonic interpreter service that provides for real-time, on demand interpretation in multiple languages to support conversations between staff and non-English speaking callers. 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 providing culturally respectful and responsive services. Our annual Family Support conference scheduled for May

2020 was focused on this topical area, but due to the pandemic the conference had to be postponed and will be offered in 2021. DDS leadership staff met with several family groups from diverse cultural and linguistic communities throughout the year to better understand their needs and concerns, answer questions, and identify ways to be more responsive.

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 and anti-racist services will continue to be provided for Family Support providers and DDS staff. Opportunities will be fostered to share strategies, resources and local partnerships that have been effective.
- Language access and culturally responsive service delivery is a major area of emphasis that has been integrated into the new procurement for family support program services in FY21.
- 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 multiple and varied 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. Inter-agency communication and coordination has been essential in working to address the COVID-19 pandemic in responsive and effective ways to support individuals with disabilities and their families.

DDS, in partnership with the Executive Office of Elder Affairs (EOEA), other human service agencies and community organizations continues to focus on respite resources for family caregivers across the lifespan. In addition, in partnership with EOEA, DPH, DMH, the Lifespan Respite Coalition and the Health Education Center at UMass Medical School, DDS is completing a three-year federal lifespan respite grant. Focused on inter-agency planning and coordination across state agencies using a common definition and lens, activities included identification of best practices, development of approaches to build synergy and improve access to resources, along with a focus on respite training to increase the pool of qualified workers to provide these services.

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, as well as strategies to make services more accessible and responsive. Funding for Memory Cafes across the state continues to provide enriching experiences and support to older individuals experiencing memory loss along with their caregivers.

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 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 has also worked closely with MassHealth to share information on the Applied Behavioral Analysis (ABA) service available through the State plan as well as other relevant services for children with Autism, to help facilitate access for children who are eligible and can benefit from these services

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. DDS family support staff and children and transition service coordinators collaborate 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 is the lead agency on a five-year federal grant from the Administration on Intellectual and Developmental Disabilities, the Massachusetts Partnership for Transition to Employment (MPTE). This system change project is 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 DESE, MRC, 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 EOEA on a variety of initiatives focused on supports for older caregivers, services and resources for individuals with Intellectual Disability who are aging, and in implementation of the Memory Cafes.
- 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 participates in the Commission on the Status of Grandparents Raising Grandchildren, a cross agency collaborative effort.
- 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.
- DDS will work in partnership with DCF and The Children's Trust along with other partners to explore ways to more effectively address the support needs of parents who live with Intellectual and Developmental Disability, through training, sharing of best practices and resources, and working to expand service capacity.