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Department of Developmental Services

Chapter 171 Report and Annual Individual and Family Support Plan

Fiscal Year 2022

November 2021



**Department of Developmental Services
Annual Family Support Plan
Fiscal Year 22 (FY22)**

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. DDS is organized into 4 regions and 23 Area Offices. Each DDS region has a Director of Family Support and each Area Office has Service Coordinators who assist and support individuals and families.

Overview of Family Support

The primary goal of family support is to provide a variety of options to individuals and their families that enable them to remain together and be contributing members in their communities. The DDS Family Support system is based on the principle that individuals and families know their own needs, and therefore the range of services is broad and flexible. DDS Family Support Centers and other family support programs are designed to be responsive to the dynamic and changing needs of the person with a disability and his/her developmental stages throughout the lifespan within the family unit.

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 designated funding for the delivery of family support services through the Respite and Family Support account in the state budget (5920-3000). In FY22, the budget appropriation is \$84,853,898 million, which reflects an increase of \$7 million from FY21. Of this total appropriation, approximately \$72 million is for specific family support services and the remainder is allocated for other community support services.

The COVID-19 public health emergency that began in March 2020 had significant impacts on DDS individuals and families, particularly for families caring for a loved one at home with complex medical needs or behavioral challenges. Since the public health emergency declaration, service providers have continued to be resourceful and responsive in addressing emergency needs and in adapting the way services and supports are offered through virtual and remote approaches. The Department's Flexible Funding Guidance was modified at the onset of the pandemic to provide more flexibility in how funding allocations could be used to support families during this time, specifically around assistance with short term basic emergency needs (i.e., food insecurity, purchasing household items including disinfectants, wipes, bleach, etc.), adaptive equipment, technology devices, as well as supplies for enrichment and leisure.

Family Support Programs have been proactive in their outreach to families, maintaining regular contact by phone and through use of social media, to provide timely information and resources related to the pandemic and for overall support. Providers offered a variety of virtual and remote programming

opportunities beneficial to both individuals and caregivers, including support groups, classes, trainings, music therapy, and stress management. Feedback from individuals and families reinforced how this array of supportive services was an important lifeline to families.

Additionally, there has been great collaboration among providers resulting in the sharing of resources, increased access to opportunities, and networking, all minimizing the barriers that sometimes occur due to geographic and transportation challenges. Family support providers and DDS staff are engaged in reflecting and learning from these experiences to better understand which practices and approaches have been effective and will be beneficial to integrate and sustain as part of future practices.

As of June 2021, there are approximately 43,200 individuals eligible for DDS services living in the community (9,470 children under 18 years old, 5,000 between 18-22 years old, and 28,700 over 22 years old). More than 24,000 children and adults live at home with their families. In addition, there are approximately 3,000 individuals with Autism Spectrum Disorder (ASD) who do not have an intellectual disability, and 12 individuals with Prader-Willi Syndrome.

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 developmental disability 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 continues to explore and evolve new service models and approaches through input from individuals and families as well as address some of the challenges by engaging individuals in the services that are available. Many adults now choose to self-direct their services through the Participant-Directed Program or Agency with Choice Self-Direction models, which enables them to tailor and customize their services in ways they view as more helpful to them.

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 approaches to help assess the Department's current system of family support services and inform areas for policy development. Through consultation and past strategic planning efforts implemented 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, easier access to information, and help navigating services.

These priorities have provided a framework for the services available through our network of 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 at <https://www.mass.gov/files/documents/2016/07/ty/family-support-report-jan2012.pdf>.

There are several longstanding groups DDS has established to gather input and obtain feedback from families and other stakeholders, including:

- The **Statewide Family Support Council**: This group includes parents from across the state who have or recently had children and adult family members with disabilities living at home with them. Council members have played integral roles in family support strategic planning processes, provided input on the recent procurement for 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.
- The **DDS Statewide Advisory Council (SAC)** and the 4 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. This past year, the SAC implemented a short survey for families to better understand their preferences and effective approaches for communicating with families during the COVID-19 pandemic.
- **Governor’s Commission on Intellectual Disability (GCID)**: The Commission is an independent citizen oversight body consisting of 13 members appointed by the Governor for a term of three years. The Commission was provided with a comprehensive scope and purpose, including the ability to review public policy in the area of intellectual disability as well as analyzing and identifying systemic areas of concern affecting the human service delivery system within Massachusetts.
- **Family and Individual Advocacy Organizations**: This includes representatives from the Arc of Massachusetts, MassFamilies, Advocates for Autism in Massachusetts (AFAM), Massachusetts Advocates Standing Strong (MASS), Massachusetts Down Syndrome Congress, the Autism Commission, and the Developmental Disabilities Council.

In FY20, DDS worked on the development of a new procurement for our Family Support Services, which was posted in February 2020 and delayed due to COVID-19, and then reposted in August 2020. This procurement includes: the Family, Cultural/Linguistic, and Autism Support Centers; the Intensive Flexible Family Support (IFFS) program; the Medically Complex program; and the Family Leadership Programs. The planning process for this procurement provided an opportunity to seek input from family members and providers to help inform ideas, changes, and priority areas to consider in the design of these services. Two sessions were held with current providers of family support services, and six forums for family members were held across the state. In addition, an online survey was developed and translated into multiple languages and was ultimately completed by more than 500 families.

Highlights and key themes that emerged include:

- Flexibility of services,
- Relationship building with families to understand their needs,
- Assistance in navigating services and other state/federal resources,
- Opportunities to connect with other families with shared life experiences, and
- Additional social, recreational, and community activities for individuals and families.

Some of the most important services and needs identified include:

- Identifying and accessing respite services,
- Flexible funding,
- Assistance with transition planning to adult services,
- Support with guardianship or other alternatives, and

- Increase individualized support services for complex medical or behavioral support needs to increase community access.

Areas identified as needing further development included:

- Outreach and communication to families regarding services and resources available to them (including local Family Support programs),
- Regular communication with use of multiple approaches reflective of the preferred modes of families (including translation/interpreter services),
- Assistance with planning at key life transition points (especially from school to adult services),
- Supports for siblings (i.e. mentors and support groups), and
- Supports for parents (i.e. increasing networking opportunities and support groups)

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

Highlights from FY21:

DDS completed the re-procurement for the Family Support Services programs we provide, which include the Support Centers (Family, Cultural/Linguistic, Autism), the Intensive Flexible Family Support program, the Medically Complex Program, and the Family Leadership Programs. This Request for Response (RFR), re-issued in August 2020, made awards and had new contracts in place for a January 1st, 2021 start date. A current listing of these Centers and programs can be found in the Statewide Directory of Family Support Services on the DDS website at <https://www.mass.gov/lists/dds-family-support-services-information-dds-family-support-directory->.

DDS completed its second year of a national *Community of Practice (CoP) for Supporting Families* hosted by the University of Missouri/Kansas City and the National Association of State Directors of Developmental Disability Services (NASDDDS). This is a partnership with the Massachusetts Developmental Disability Council. The goal of this three-year initiative is to build capacity, through 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. This past year a Statewide CoP Stakeholder Network was established to work collaboratively and develop how we engage and work with families using the Charting the LifeCourse framework and tools. This has led to strong engagement with the Massachusetts Department of Public Health (DPH) and the Department of Elementary and Secondary Education (DESE) along with other providers and family members.

DDS provided more flexible funding resources to families which were instrumental in coping with the COVID-19 pandemic by helping address emergency and other basic support needs. Specific flexible funding in the amount of \$60,000 was designated to support older caregivers, most of whom were age 75 or older, who have their adult family member at home. About 60 families benefitted from this funding made available through 4 Area Offices and Family Support Centers across the state. These one-time resources made a big difference in the lives of these families. Many used this for respite to have some personal time for themselves, while other uses included necessary household items and resources to address short-term emergency needs. A “Caregiver Appreciation” webinar series, in partnership with The Arc of Massachusetts, was also offered from November through March on topics focused on self-care and support for parent caregivers.

DDS continues to provide training and related learning opportunities for DDS Service Coordinators, family support providers, family members, and self-advocates 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 pursue their life aspirations in the community. DDS works in partnership with other stakeholders to support the integration of these practices in our work with individuals and families. In partnership with the Arc of Massachusetts, DDS developed 25 short videos of family members, professionals, and individuals highlighting how this framework is helpful in planning and problem-solving. These were shared widely through social media and are posted on a new webpage at www.thearcofmass.org/lifecourse.

Focus Areas: Review of Activities and Accomplishments in FY 2021 and Proposed Initiatives for FY 2022.

The following section provides brief highlights of ongoing efforts as well as new activities the Department has undertaken this past year and includes 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 initiatives through a variety of organized groups and mechanisms, which has informed and helped shape programmatic decisions 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 enacted in 2014 includes adults who are actively engaged in self-directing their services. Their input and experiences have helped inform the evolution of self-directed service options that include Agency With Choice (AWC) and the Participant-Directed Program (PDP), including ways to help educate and inform other consumers about the benefits of these program opportunities.

Individuals with disabilities and family members participate on the Department's **Statewide Quality Council** to assist in reviewing evaluation data about the quality of services provided and to identify areas for enhancement as part of a continuous quality improvement process. Family member engagement is central to 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.

DDS also worked on the development of a new procurement for our Family Support Services, which was posted in February 2020 and delayed due to COVID-19, and then reposted in August 2020. This procurement includes: the Family, Cultural/Linguistic, and Autism Support Centers; the Intensive Flexible Family Support (IFFS) program; the Medically Complex program; and the Family Leadership Programs. The planning process for this procurement provided an opportunity to seek input from family members and providers to help inform ideas, changes, and priority areas to consider in the design of these services. Two sessions were held with current providers of family support services, and six forums for family members were held across the state. In addition, an online survey was developed and translated into multiple languages and was ultimately completed by more than 500 families. Some of the most important services and needs identified includes:

- Identifying and accessing respite services,
- Flexible funding,
- Assistance with transition planning to adult services,

- Support with guardianship or other alternatives, and
- Increase individualized support services for complex medical or behavioral support needs to increase community access.

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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 principle that individuals and their families are recognized as primary decision makers about their lives and supports. Therefore, service 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. The most frequently identified areas include respite to provide a break to caregivers, social and recreational opportunities along with supports for individuals to meaningfully participate in these activities, help accessing adaptive equipment and supplies including technology, and assistance accessing community resources. A small group of Council members worked closely with DDS staff in the development of a companion manual, “Supporting Families: A Guide for Family Support Services” which will be made available in November 2021. Specific attention is being paid to providing information in a way that is accessible to families from different cultural and linguistic communities. This Guide will be translated into multiple languages, and in the development of this guide input from family members and community leaders from cultural and linguistic diverse communities was obtained for input on how to more simply describe services and the eligibility process, and overall to help ensure the reading level used would make the Guide more accessible.

The DDS 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 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 agency they have in 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 service models. DDS has established funding resources for a Speaker’s Bureau to compensate individual and family presenters who share their stories and experiences.

There has been growth in the number of individuals engaged in self-directing their services over the past several years. During COVID, many individuals and families have sought out this alternative in order to develop more flexible support options, since many traditional services were not available due to health and safety restrictions. As of June 2021, there are about 700 individuals/families using the AWC model and about 988 individuals/families engaged in self-direction through the PDP.

Two of the specialized programs for children/young adults, the DESE/DDS Program and the Autism Waiver Program, are structured to support family empowerment. They provide families the opportunities to direct service and budget planning as well as have a role in the selection of staff that will provide these 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. Two new waiver services will be available in FY22, Assistive Technology and Remote Supports and Monitoring, which will increase access to supportive technology and promote independence.

Assistive Technology (AT) Services consist of three distinct components:

- Assistive Technology Evaluation of the assistive technology needs of an individual, including a functional assessment of technologies available to address the individual's assessed needs and support the individual to achieve outcomes identified in his or her individual support plan.
- Assistive Technology Devices covers the cost of assistive technology equipment consistent with the AT assessment.
- Assistive Technology Training includes the set-up of AT equipment, education and support that aids an Individual in the use of assistive technology equipment and devices as well as training for the individual's support network (paid/unpaid) or who are otherwise substantially involved in activities being supported by the assistive technology equipment and devices

Examples of Assistive Technology:

- Sensors that detect that a stove has been left on
- Augmentative Communication Devices
- Telephones with modifications such as large buttons, picture buttons or flashing lights
- Voice activation of lights, appliances, doors, etc.
- Bracelet that detects seizure activity

Remote Supports and Monitoring (RSM) is an emerging service model that combines technology and direct care professionals to support people with developmental disabilities. Remote support uses two-way communication in real time, including home-based sensors, audio devices, and other technologies, to allow an off-site staff to provide guidance and support as well as monitor and respond to the safety and needs of people living in the community. When hands-on care is not required, remote support can offer a variety of individualized supports through technology that increase independence, build upon strengths to enhance skills, and increase opportunities for self-advocacy and driving one's own life.

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 to provide education, leadership training, and mentoring for families of children and adults with disabilities. Three of these family leadership programs are implemented by MassFamilies and they work in partnership to coordinate activities with the other two regional programs. The training and mentoring components of these programs are 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. Through these trainings, there have been concerted efforts to attract and support families from different cultural and linguistic communities. Due to COVID-19 and restrictions on in-person events, all training activities had to be modified this past year and have been offered virtually. 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. Some examples include participation on local/regional Disability Commissions; running for School Committee and SPED Parent Advisory Councils; participating on advisory groups and councils

with DDS and other state agencies such as DPH; providing training and peer support to other family members; and becoming involved in legislative activities including advocacy for passage of new bills that will make a positive difference in the lives of people with disabilities and their families.

A variety of other training opportunities are offered, including an Advocacy Bootcamp for younger families and a training series called “A Full Life Ahead.” This series 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 and leadership skills. 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?

With the procurement of our Family Support Centers and Autism Support Centers in FY21, DDS re-emphasized the requirement for centers to develop Advisory Councils in order to give families and individuals the opportunity to influence their priorities for services, supports, and programming at a local level. These Advisory Councils will provide consultation to the Family Support Implementation Work Group in updating and refining quality assurance activities at the centers and other activities. In addition, as DDS receives American Rescue Plan Act (ARPA) funding this year, the Department will seek input at all levels – including these Advisory Councils, our Statewide Family Council, and Citizen Advisory Boards – to shape the direction of new initiatives and the expansion of family support services. Finally, DDS will also utilize family leaders to share their perspectives, experiences, and knowledge at the annual Family Support Conference, which will drive content development and serve as an integral component of sessions to ensure their voices are heard and acknowledged.

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 available 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, and other activities. Additionally, Service Navigation is offered in order to provide individualized and comprehensive information, guidance, and support to families. This helps their needs in being addressed, connects them to potential resources, assists them with problem-solving, and aids them in navigating the service system. Centers administer flexible funding resources to families who are prioritized to receive an individual allocation, which can be used to purchase allowable services and goods as defined in the Department’s 2019 Family Support Program Manual and Guidelines. There are 35 Centers funded across the State with funding totaling approximately \$14.6 million. These Centers, along with the Cultural/Linguistic Specific Centers described below, provide some type of individualized assistance to

more than 13,000 families a year in addition to many more through information and referral, trainings, and recreational or community events. These Centers also administered approximately \$12 million dollars in flexible funding allocations to families.

Cultural/Linguistic Family Support Centers are designed to respond to the unique needs of 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 assistance in learning about and accessing the service system and the related supports. These Centers offer a similar array of services as the Family Support Centers described above. There are eleven Cultural/Linguistic Family Support Centers with funding totaling approximately \$1.8 million.

Autism Support Centers provide an array of information and referral services, resources, and supports to children with ASD and their families. Over the past five years, these centers have expanded their focus to also support a growing number of adults with ASD, who do not have ID, 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 to engage adults with ASD in activities and support services while also providing assistance to their families.

Historically, there have been a total of 5 large and 2 smaller regional autism support centers. As a result of the recent family support services procurement and the growing number of adults with ASD who do not have ID now eligible for DDS services, there are a total of 9 centers organized to meet the needs of individuals in the area they serve. There are 2 centers that provide services to both children and adults with ASD without ID, 5 centers that serve children and their families, and 2 that are designed only for adults with ASD (without ID) and their families. In FY21 they were funded at almost \$3.5 million, which covers the community-based 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 experiences that many 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 services are designed to assist families of children between the ages of 3 and 22. Annually, about 675-700 children and their families receive services through the 23 regional and area-based programs across the State, funded at approximately \$3.3 million.

Medically Complex Programs support families who are caring for children/young adults up to the age of 25 with significant cognitive, physical, and 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 400-425 individuals and their families. These five regionally based programs are funded in total at approximately \$770,000.

The Department also operates a **Medical Respite Home** in Southeastern Massachusetts 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 evolved to include transportation, a variety of community-based activities, and other supports to assist individuals and families. Approximately 66

individuals have completed the intake process for the respite home. During FY20, 42 individuals and their families used this resource for a total of 385 overnight stays. The respite home needed to close in March 2020 due to COVID-19 and has not yet re-opened, but is anticipated to begin providing overnight respite sometime in Fall 2021. This service provides important relief and respite for families and an enriching social experience for the adults.

Family Leadership Development Programs provide education, mentoring, and support to families. A comprehensive and intensive family leadership series is offered, providing information and education about “best practices” and helping 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 5 regionally based Family Leadership Programs funded for a total of approximately \$520,000.

The **DDS Autism Division** is funded at \$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 and 380 children across the year. An open interest period is held annually to provide families an opportunity to identify interest in having their child be considered for this program. This Waiver Program was renewed for another 5 years beginning in October 2020, which increased 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. Over the five-year period, enrollment will grow to 340 children and 440 children across the waiver year.

This past waiver year has been impacted dramatically by Covid-19 and has required a number of programmatic adjustments. MassHealth and DDS sought and received permission for additional flexibilities, Appendix K, from The Centers for Medicare and Medicaid Services (CMS). Both MassHealth and DDS solicited input from families to inform these changes which included the addition of a home delivered meal service, the delivery of Education Habilitation and Behavioral Consultation services via telehealth, increases in the prospective budget caps, the elimination of in person meetings, an allowance for electronic signatures across program documents, and permission to allow children over the age of 9 to remain in the program throughout the Appendix K flexibility period. Other significant changes included:

- Increasing maximum waiver capacity and point- in- time limit in waiver years 1-5
- Updating the Family Training service to focus on identifying barriers, facilitating readiness and enhancing family engagement through the addition of new service levels
- Increasing the individual prospective budget limit for \$25,000 to \$28,00 and removing the cost of fences and other home modifications from the individual’s annual limit
- Increasing the individual prospective budget limit for ancillary services from \$5,500 to \$6,000
- Increasing the annual limit for Individual Goods and Services from \$1,000 to \$ 1,700
- Increasing the annual budget for individuals in the step-down from \$7,500 to \$8,500
- Increases to providers rates to align with rates for parallel services from other public funding sources

The Autism Division also helps fund a specialty community program designed to train first responders called the Autism and Law Enforcement Education Coalition (ALEC). ALEC has trained state police, multiple municipal police, fire and first responders across the Commonwealth. The trainers are family members of individuals with Autism Spectrum Disorders who professionally are First Responders which gives them instant credibility with their peers. ALEC has a standard curriculum which has been used as an example in training the State Police, the Boston Police Department and state fire academy etc. To date, thousands of first responders in the state have gone through this training. Based on ALEC’s work they

have been awarded Federal Emergency Management Act (FEMA) grants and offer this training in other states across the country. This program remains a successful initiative and has received national recognition.

The Department of Elementary and Secondary Education & Department of Developmental Services Community Residential Education Program (DESE/DDS) is a collaborative initiative designed to provide supplemental supports to children/young adults in order 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 FY21, DDS continued to receive \$10.5 million for the program. The program supported 809 participants between the ages of 6 to 22, with 23 of these participants aging out of the Autism Waiver program and meeting the criteria/eligibility for the DESE/DDS program.

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 also 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 service systems. Centers use a variety of approaches to disseminate information to families, including email, websites, online newsletters and training calendars, webinars, and social media, and maintaining a "library" of resources. Centers also 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 other community-based organizations.

When individuals are found eligible for DDS services, families are sent a "welcome flyer" with information about their local Family and Autism Support Centers. This provides families who are not already connected to a local Center with the information they need to make that contact and 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. The Directory is widely disseminated through DDS, service providers, and is posted on the DDS website at <https://www.mass.gov/lists/dds-family-support-services-information-dds-family-support-directory>. 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 platforms, including Facebook, Twitter, Instagram, and LinkedIn to communicate with individuals and families to provide information, resources, and updates in a timely manner.

DDS continues to provide funding for "Pathways to Friendships: 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. It offers a train-the-trainer series as well as

consultation and mentoring to other provider agencies on ways to foster community membership and friendships. A website entitled, “A Toolkit for Community Recreation, Cultural, and Faith Organizations” was created with resources focused on practical information and strategies for community organizations to be welcoming to people with disabilities, and is available at <https://thearcofmass.org/friendship>

DDS continues to provide opportunities for staff and families to become exposed to and learn more about the Charting the Life Course 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, best 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). In addition, 25 short videos were developed and shared widely through social media highlighting the stories and experiences of families, self-advocates, and professionals who found this framework and tools helpful in their own lives. These are based on the power of micro-messaging and was a partnership with The Arc of Massachusetts. More information can be found at www.thearcofmass.org/lifecourse.

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 offered an opportunity to learn more about the current needs of parents, services, and resources that are available to enhance the supports available to parents, providers, and staff who are working to assist them. A resource directory is currently being finalized (will be available electronically in January 2022) and several training opportunities were provided to about 42 family support practitioners across the state in order to enhance their knowledge, expertise, and resources to support individuals in their parenting role.

DDS also helps make services accessible to families through funding support for New England INDEX, including the Autism Insurance Resource Center which provides information, training, and consultation about the Massachusetts Autism Insurance Law (An Act Relative to Insurance Coverage for Autism, or ARICA). DDS also offers many presentations on DDS services and the eligibility process for families and other professionals, and hosts resource tables at other statewide conferences for families such as the annual conference sponsored by the Federation for Children with Special Needs, which the transition conference sponsored by The Arc of Massachusetts.

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.

Forums on Turning 22, the transition process from school to adult services, will continue to be sponsored for families by DDS Area Offices in partnership with local Family Support Centers, school districts, and other providers to help families understand this planning process and learn about adult service options and providers.

DDS continues to provide funding support for the web-based Rewarding Work Respite Directory (<https://www.mass.gov/rewarding-work-respite-and-in-home-care>) that provides a directory 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 website 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. 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 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 and DESE/DDS Programs. Interpretation and translation services are provided as an integral part of these services.

DDS makes available interpreter services and translates informational materials for individuals and families in multiple languages. Effective working relationships have been established with several interpretation and translation services, and as a result these entities have developed a good understanding of disability terminology and concepts which leads 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 primary language.

DDS will continue to offer training opportunities for family support and DDS staff focused on providing culturally respectful and responsive services. In addition, DDS leadership staff meet 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. This helps promote increased understanding of different cultural and linguistic groups and supports the delivery of more culturally responsive services. There is also a strong commitment to racial equity and justice, and there are numerous ways staff can take advantage of different learning about opportunities to have conversations with colleagues and others about their experiences.

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. In addition, opportunities will be developed to hear directly from individuals and families from diverse communities to enhance our understanding of their experiences and what is helpful to them.

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. This is an area for continued development and will be an important area of focus. 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 a variety of inter-agency activities with other Executive Office of Health and Human Services (EOHHS) agencies to promote more effective service delivery and to maximize resources. DDS Regional and Area Office staff participate in local inter-agency planning teams to promote more effective communication and to work toward coordination and collaboration in service delivery when there are individuals involved with multiple agencies. In particular, inter-agency communication and coordination has been essential in working to address the COVID-19 pandemic in responsive and effective ways that 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 continue to focus on respite for family caregivers across the lifespan. DDS, in partnership with EOEA, DPH, DMH, the Lifespan Respite Coalition, and the Health Education Center at UMass Medical School will be completing a three-year federal lifespan respite grant that runs through August 2021. Focused on inter-agency planning and coordination across state agencies using a common definition and lens, activities have included identification of best practices, development of approaches to build synergy and improve access to resources, and a focus on respite training in order to increase the pool of qualified workers that can provide these services.

DDS staff continue to collaborate with staff from EOEA, 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 have continued 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 DMH 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, DMH, and the Department of Children and Families (DCF) on the implementation of the Children's Behavioral Health Initiative (CBHI). An area of ongoing focus has been to identify approaches for these services that can be 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 (UPT) meetings when requested for individuals who are eligible for DDS services and offer consultation on children who are not eligible for DDS services. DDS Family Support Center staff, DDS Children Service Coordinators and DDS Transition Service Coordinators collaborate with the DPH 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 has been 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 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. Although the grant program will formally end in September 2021, the cross-agency collaboration will continue.

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, the Massachusetts Rehabilitation Commission (MRC), and the Executive Office of Labor and Workforce Development (EOLWD), complemented by diverse representation of family advocacy groups, self-advocates, local school system representatives, employment provider agencies, and other stakeholders.

Other key activities and/or initiatives include:

- DDS staff will continue to work closely with EOEA on a variety of initiatives focused on supports for older caregivers and services and resources for individuals with Intellectual Disability who are aging.
- DDS and DMH will continue to develop and implement joint agency plans to better support adults with ASD with 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.