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Department of Developmental Services

Chapter 171 Report and Annual Individual and Family Support Plan

Fiscal Year 2023

November 2022

Department of Developmental Services
Annual Family Support Plan
Fiscal Year 23 (FY23)

Overview

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.

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 was $84,853,898. Of this total appropriation, approximately $72 million is for specific family support services and the remainder is allocated for other community support services. For FY23, the budget appropriation is $90,230,299, an increase of more than $5 million over FY22.

As of June 2022, there are approximately 44,000 individuals eligible for DDS services living in the community. Of the eligible population: 9,700 are children under 18 years old, 5,100 are between 18-22 years old, and 30,000 are over 22 years old. More than 25,000 children and adults live at home with their families. In addition, there are approximately 3,600 individuals with autism spectrum disorder (ASD) who do not have an intellectual disability, and 14 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 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 the framework for the services available through our network of family support services

In FY20, DDS worked on the development of a new procurement for our Family Support Services. This procurement included: 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.

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.
- **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.

Highlights and key themes that emerged from these groups 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),
- Improved engagements skills and efforts,
- Regular communication with use of multiple approaches reflective of the preferred modes of families (including translation/interpreter services), plain language,
- 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)

Highlights from FY22:

With the expansion funds received in FY22, DDS focused on rebuilding our respite capacity so that families can have more opportunities to predictable, planned and accessible respite support. These efforts included expanding and opening four facility-based programs. In addition, we developed and offered weekend daytime respite and increased social and recreation opportunities. DDS increased flexible funds to more families and increased the amount for many families enabling them to purchase respite themselves or to use these funds in ways that they determine will positively affect their family.

In some areas of the state, DDS increased the staffing at our Family Support Centers to provide more targeted outreach and connection to under resourced communities – which included rural areas and areas with underserved populations.

Family Support Quality Assurance activities resumed in FY22 which include Family Support Center Semi-Annual and Annual Data Reports, Family Support Flexible Funding Review Process, Family Support Center Quality Reviews and Family Input and Satisfaction Surveys with Family Support Programs. Through advisement of the **Family Support Council,** DDS will use a neutral entity to survey families about their experiences with the Family Support Centers in FY23 to ensure we receive authentic feedback to ensure program quality and effectiveness.

In September of 2022, DDS will host an in-person statewide Family Support Conference, “Making a Cultural Commitment: Bridging Cultural and Linguistic Gaps”. This conference will focus on enhancing provider capacities and skills around cultural competencies to improve how we serve our diverse consumer populations as well as how to expand community connections and partnerships to increase access and awareness of our services.

Understanding that individuals continue to have limited or restricted access to in-person schooling or day/employment programs, DDS will use American Rescue Plan Act (ARPA) funding in FY23 to increase access to respite services for caregivers to provide some relief. DDS has focused on expanding our facility-based respite with an emphasis on respite for individuals with medically complex needs, full-day weekend respite options, school vacation camp programs, hotel respite and increasing the number of families with flexible funding to procure their own respite providers.

In partnership with the Massachusetts Developmental Disability Council, DDS completed its third and final year of the "*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). The goal of this 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 individuals and families across the lifespan. This past year, a statewide "CoP" Stakeholder Network was established to work collaboratively with families using the Charting the Life Course framework and tools. This has led to strong engagement with the Massachusetts Department of Public Health (DPH) along with other providers and family members.

DDS provides training and related learning opportunities for DDS Service Coordinators, family support providers, family members, and self-advocates on *Charting the Life Course,* in partnership with the Arc of Massachusetts (see link for further information: www.thearcofmass.org/lifecourse). In addition, DDS and the Arc of Massachusetts partner with the Institute of Community Inclusion (ICI) to host monthly "Tools in Action" – a virtual series to provide individuals, families, caregivers, advocates and others the opportunity to hear how individuals/families are utilizing the framework and to help guide them in person-centered problem solving and planning.

Focus Areas: Review of Activities and Accomplishments in FY 2022 and Proposed Initiatives for FY 2023.

The following section provides 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

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 have informed programmatic decisions and identified priority areas in supporting families caring for their loved one at home. The statewide **Self-Determination Advisory Board**, established to support the 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.

In FY22, DDS partnered with the Center for Developmental Disabilities Evaluation and Research (CDDER) Center at UMASS in a needs assessment on Aging Caregiver Support. The focus was on family supports and the needs of aging parents, siblings and other non-paid caregivers of adults with I/DD. Input was gathered through focus groups with community organizations, DDS Service Coordinators, Family Support Centers, Parent/Caregiver groups and individual interviews. The results of the needs assessment highlights how older and/or aging caregivers are navigating/accessing services, how DDS engages these families and opportunities for improvement in meeting evolving and changing needs of these families. DDS and CDDER are currently reviewing the survey results and will be working with our provider networks, the Executive Office of Health and Human Services, the Executive Office of Elder Affairs and other stakeholders including the Massachusetts Sibling Support Network and the Arcs: Center for Future Planning to implement needed services in FY23.

DDS consumers 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 the driving force behind how we assess and enhance our varying service models and offerings.

Each Family Support Center is required to establish an **Advisory Council**, made up of family members and individuals with disabilities who represent the diversity of the communities we serve, including different age groups, races and cultures, linguistic and communication abilities, types of disability, etc. The intent of these Councils is to help inform the interests, needs, and priorities of families and individuals; promote geographic access to services; and help solicit and use input and feedback from families regarding satisfaction and quality of services provided. The **Advisory Councils** are expected to convene either in-person or by using technology to provide input through phone or videoconferencing, email, and other means of communication that facilitate participation for all members. Feedback from these groups will be reviewed with our Regional Family Support Directors, and our Area Office staff, and this input is used to inform and improve our family support systems.

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 respond to unique needs, strengths and cultural values of each individual, family and community we serve. DDS has laid out clear expectations for Family Support Centers to establish their Advisory Councils and solicit consistent feedback to share with DDS Area and Regional Offices to continue meeting this goal of being responsive, fluid and effective in responding to our consumers and community needs. DDS Area Offices meet quarterly with each Family Support Center to review the Center's activities inclusive of contract status, workforce status, center activities and discuss feedback provided from families either learned from council meetings at the center or feedback provided directly to the Area Office from families.

DDS also engages our **Statewide Family Support Council** on a number of initiatives involving our Family Support Centers and services. For example, members provided important and helpful input in the development of the new *Family Support Program Manual and Guidelines*, https://www.mass.gov/2019-family-support-program-manual-and-guidelines and a companion manual, "Supporting Families: A Guide for Family Support Services." The companion manual is being finalized now with special advisement and attention being paid to making these manuals accessible (use of simple language), available in multiple translations and culturally competent to ensure accessibility to this information.

There has been growth in the number of individuals engaged in self-directing their services over the past several years and even more in the last year as a result of the workforce challenges and the length of time it has taken day/employment options to re-open fully. During the pandemic, many individuals and families have sought out this alternative in order to develop more flexible support options. DDS Regional Self-Direction Managers engage in regular outreach to individuals and families and host forums with a variety of partners, including Family 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. Participants play an important role in sharing their experiences to help educate others about the opportunities to engage in self-direction service models, so much so that DDS has allocated funding resources to support a Speaker's Bureau to compensate individual and family presenters to share their stories and experiences to promote this person-centered service model. You can access these stories at https://www.mass.gov/service-details/real-lives-real-stories.

Two of DDS' specialized programs for children/young adults, the DESE/DDS Program and the Autism Waiver Program, are structured to support family empowerment by providing them the opportunities to self-direct services and budget planning as well as have a role in the selection of staff that will provide supports. Both service models are intended to keep I/DD youth in their homes and in less restrictive settings through specialized services geared for individualistic needs, disabilities and learning styles.

The DDS Adult Home and Community Based Waiver Programs also provide opportunities for individual and family empowerment through choice in service delivery approaches, service providers and portability of services. Two new adult waiver services became available in FY22, Assistive Technology and Remote Supports and Monitoring, which will increase access to supportive technology and promote independence; specifically, these supports include:

Assistive Technology (AT) Services:

- 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

Remote Supports and Monitoring (RSM): This 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

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, who works in concert with the other two programs to ensure activities and training offerings are consistent and uniformly available throughout the state. The training and mentoring components 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, so trainings are offered in alternate languages including Spanish and Portuguese. Graduates of this series move into new leadership roles in a variety of capacities and play active 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; 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.

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. MassFamilies partnered with DDS to host a series called "Real Talk: Black and Brown Conversations" which explored the experiences of black and brown families caring for and/or providing services to someone with disabilities. Collectively, hundreds of families across the state are reached through these trainings and activities annually.

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 provide both individuals and families the opportunity to voice their priorities, interests and needs.

Through our Family Support Center providers, DDS offers workshops and training *in Charting the Life Course* directly to families and encouraging the use of the principles, framework and tools. It is designed to organize ideas, visions and goals, problem-solve and navigate varied state and community-based systems available to support individuals and their families. The framework and tools can lead individuals and families to be focused on their person-centered advocacy as well as advocacy in macro systems.

III. Family Support Resources and Funding

DDS **Family Support Centers** are 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. There are 33 Family Support Centers funded across the State with funding totaling approximately $14.9 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.

Family Support 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. Centers administer flexible funding resources to families, which can be used to purchase allowable services and goods as defined in the Department's 2019 Family Support Program Manual and Guidelines. These centers administered approximately $14 million in flexible funding allocations to families, providing them 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 of need 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.

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 individuals and families served – leaving many to 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 ten Cultural/Linguistic Family Support Centers with funding totaling approximately $2.5 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 six 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 seven Autism Support Centers, but as a result of the recent procurement there are a total of 9 centers throughout the state. In FY22, Autism Support Centers 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 these services which are funded at approximately $3.9 million annually.

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. These programs are celebrating their 25th year of operations.

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 in FY23 when appropriate nursing capacity is staffed.

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 five regionally based Family Leadership Programs funded for a total of approximately $580,000.

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 FY22, DDS continued to receive $10.5 million for the program. The program supported 825 participants between the ages of 6 to 22.

In FY22, the **DDS Autism Division** was funded at $7,433,900 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 10 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. The projected Autism Division budget in FY23 is $13,933,900 from the Conference budget pending approval of the Governor.

This past waiver has continued to be impacted dramatically by Covid-19 and has required the continuation of a number of programmatic adjustments. MassHealth and DDS have continued to operate under the Appendix K flexibilities provided 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.

Under the American Rescue and Recovery Act (ARPA), MassHealth and DDS plan to expand the Children's Autism Waiver program to serve an additional 225 children between now and March 2025 to bring the total number of children served to more than 500 children which was one of the original goals of the first Autism Commission. Work is underway to expand the infrastructure of the program at the Department of Developmental Services. Once that is accomplished and enrollment begins to climb, DDS intents to make investments in the Autism Support Centers to support additional Autism Waiver brokers.

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 thousands of first responders across the Commonwealth including the State Police, the state fire academy, and multiple municipal police and fire departments. The trainers are family members of individuals with autism spectrum disorder who professionally are First Responders. 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.

IV. Accessing Services and Supports

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 contact 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 which 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. This fall, DDS will be issuing a newsletter to all families with relevant information on Family Support Services and how to access them.

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. 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.

DDS continues to be engaged with other state agency partners including Department of Children and Families and the Children's Trust, and community providers in supporting parents living with intellectual and developmental disabilities. This group hosted a statewide forum in January 2022 for over 100 stakeholders who had attended the The Association for Successful Parenting (TASP) training in 2021 and/or participated in a roundtable in 2019. The goal of the forum was to build our capacity in supporting these families and to enhance knowledge, expertise, and resources to support individuals in their parenting role. In May 2022, we hosted two regional forums which resulted in discussions about collaborations between state agencies in the provision of supports and services; training for parents that is provided in a range of learning styles, use consistent materials across the state; and support for best practices and peer time to share and ask questions. The resource directory, "Supporting Parents with I/DD - A Directory of Integrated Supports" was also distributed to agencies and providers supporting parents with I/DD.

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 and the transition conference sponsored by The Arc of Massachusetts.

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. This overview was recently presented to the Community Partners at the Executive Office for Health and Human Services.

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. This resource has been updated and enables those seeking workers to navigate the site in different languages and updated job title and descriptions to better match the vocabulary that families and providers use.

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. Forums continued to be provided virtually in all regions and covered content is included in our online publication at https://www.mass.gov/doc/transition-information-fact-sheets-english/download

V. Culturally Competent Outreach & Support

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. Several centers have dedicated staff who are bi-lingual and can meet the needs of the local communities.

DDS makes available interpreter services and translates informational materials for individuals and families in multiple languages regarding all our service models, eligibility criteria and other pertinent agency information. 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.

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.

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.

DDS held a Family Support Conference in September 2022 which provided knowledge, skills, and ideas for Family Support navigators and Service Coordinators to engage with individuals and families in a more culturally competent manner. The title of the conference, “Making a Cultural Commitment: Bridging the Cultural and Linguistic Gaps”, ensured that Family Support Navigators and Service Coordinators are trained in best practices from both a family’s perspective and through Family Support Centers with experience and success in cultural brokering. As an example, part of the curriculum included a session on cultural humility where staff examined their own beliefs and cultural identities; heard from a panel of families who shared how disability is viewed within varying cultures, values and belief systems; and how that influences access and willingness to engage in services. The goal was to provide tools and strategies for agencies to be more helpful to bridge these differences and provide more responsive services.

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

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 their lifespan. DDS, in partnership with EOEA, the Department of Public Health (DPH), the Department of Mental Health (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 focuses 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 was awarded another lifespan grant through fall of 2026 – so this work will continue while also focusing on enhancing training, increasing cultural representation in the respite workforce and targeting underserved populations across the lifespan.

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.

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 formally ended in September 2021, the cross-agency collaboration still continues.

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 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 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.