



**Commonwealth of Massachusetts
Department Of Developmental Services**

***FAMILY SUPPORT PROGRAM
MANUAL and GUIDELINES***



January 2019

Massachusetts Department of Developmental Services FAMILY SUPPORT PROGRAM MANUAL and GUIDELINES

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Message from Commissioner Jane Ryder

It is my pleasure to share with you the *2019 Family Support Program Manual and Guidelines*. As Commissioner and also as a family member myself, I understand and recognize the importance of developing strong relationships and partnerships with families, and providing an array of flexible services to support families in their caregiving journey. Supporting families of children and adults through different life stages is at the heart of the Department's family support system.

This manual provides comprehensive information about the array of different family support services, includes helpful resources, and outlines procedures and guidelines to promote enhanced consistency and quality of supports. This manual not only confirms policies and procedures, but equally important, reaffirms our core principles and values to support and enable individuals with disabilities and their families to lead full, rich lives and be welcomed, contributing members of their communities. These values are what drive us to enhance opportunities for individuals to be meaningfully engaged in their community by using a combination of resources and supports that foster inclusion and capitalize on the unique gifts, talents, and dreams of individuals. These values are what drive our commitment to reaching out to diverse communities and ensuring that family supports honor the cultural, religious, and linguistic differences of families across the state.

This *Family Support Program Manual and Guidelines* has been developed in partnership with families, family support providers, and DDS staff from across the state. I want to thank everyone who contributed to the development and review of this manual.

And I want to thank family support providers and DDS staff for your ongoing commitment, the valuable role you play, and the important work you are engaged in to support families across the lifespan.

The Department affirms our ongoing commitment to supporting families and the pivotal role that families play in the lives of their children or relative with a disability. We are invested in strengthening our partnerships and pursuing innovative approaches and services to help individuals and families live a "good life."

INTRODUCTION

The Department of Developmental Services (DDS) is pleased to provide the DDS **FAMILY SUPPORT PROGRAM MANUAL and GUIDELINES**. The Department has created this Family Support Program Manual and Guidelines to serve a number of purposes;

- (1) to underscore its strong commitment to support the pivotal role that families play in the lives of their family members with intellectual and/or developmental disabilities across the lifespan;
- (2) to provide a repository of current policies, operational procedures and forms related to the implementation and monitoring of family support programs and services; and
- (3) to offer an essential reference tool for training and mentoring of DDS and family support provider staff in family support programs and policies.

The **FAMILY SUPPORT PROGRAM MANUAL and GUIDELINES** (referred to as the “Manual”) has been developed as a resource tool for Department of Developmental Services and its contracted Family Support Agencies staff to support their important work and relationships with individuals with intellectual and developmental disabilities and their families.

To the extent the provisions of this Manual conflict with DDS regulations, 115 CMR 1./00 et seq., or other applicable statutes or regulations, statutes and regulations are controlling.

HOW TO USE THIS MANUAL

The Manual contains a wealth of information about the DDS family support system, including its guiding principles of family support, its array of family support services, its policies and procedures related to family support and its quality assurance mechanisms. In order to provide a comprehensive overview of the Department of Developmental Services family support system, there are sixteen sections in the Manual which provide a great amount of detailed information, resources and guidelines, including an Appendix. It would be advantageous initially to take the time to develop a general familiarity with the entire manual. However, each section can be easily accessed through the Table of Contents and many can be utilized as an individual resource. The manual is organized in a way that lends itself to being updated on an on-going basis. The latest version of this manual will be posted on the DDS website at www.mass.gov/dds.

Sections I –IV provide an overview of the guiding principles of family support which lay the foundation for the development and implementation of family supports; offer a general description of the current array of family support services in the state; and reinforce how family supports must be responsive to individual and family needs and be culturally competent. **Section V** discusses the steps in the eligibility process for the Department of Developmental Services, including family supports. **Sections VI – VIII** describe in detail each of the family support program services, the process for the administration of individual flexible funding allocations and other unique DDS family support services and options. **Sections IX-XI** discuss the roles of the Department of Developmental Services and its Family Support Provider Agencies in the development, operation and monitoring of family support in partnership with families, as well as DDS relationships with other state agencies. **Sections XII and XIII** share the various data collection/reporting and quality assurance mechanisms that the Department uses to measure the overall effectiveness and impact of its family support services. **Section XIV and Section XV** include a listing of other important family resources and information, as well as several basic Family Support Fact Sheets. **Section XVI** displays the current family support forms and annual reports used by DDS and its family support agencies in the planning, implementation and evaluation of family support services, as well as attached guidance in their application.

Acknowledgements

The Department of Developmental Services would like to thank and acknowledge the contributions of family members, family support providers and DDS Staff who have provided valuable support, guidance and feedback in this Family Support Program Manual and Guidelines.

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and other individuals who have
contributed photographs to this manual.*



ACRONYMS

A

AAIDD - American Association on Intellectual and Developmental Disabilities, <http://www.aaidd.org>

ADA - Americans with Disabilities Act

ADD - Attention Deficit Disorder

ADDP - The Association of Developmental Disabilities Providers, <http://www.addp.org>

ADHD - Attention Deficit/Hyperactivity Disorder

ADL - Activities of Daily Living

ASC - Autism Support Center

ASD - Autism Spectrum Disorder

ASL - American Sign Language

B

BSEA – Bureau of Special Education Appeals

C

CAB - Citizen Advisory Board

CBHI – Children’s Behavioral Health Initiative

CMS - Centers for Medicare and Medicaid Services

CORI - Criminal Offender Record Information

CP - Cerebral Palsy

CRA – Child Requiring Assistance

CRT - Complaint Resolution Team

CSHCN - Children with Special Health Care Needs

D

DCF - Department of Children and Families, [Department of Children & Families](http://www.mass.gov/children)

DD - Developmental Disability

DDS - Department of Developmental Services, <http://mass.gov/dds>

DEEC – Department of Early Education and Care, <http://mass.gov/eec>

DESE – Department of Elementary and Secondary Education, www.mass.gov/DESE

DHCD – MA Department of Housing and Community Development, <http://www.mass.gov/dhcd>

DLWD - Department of Labor and Workforce Development, <http://www.mass.gov/dlwd>

DMH - Department of Mental Health, <http://www.mass.gov/dmh>

DPH - Department of Public Health, <http://www.mass.gov/dph>

DPPC - Disabled Person's Protection Commission, <http://www.mass.gov/dppc>

DTA - Department of Transitional Assistance, <http://www.mass.gov/dta>

DX - Diagnosis

DYS - Department of Youth Services, <http://www.mass.gov/dys>

E

EI - Early Intervention Services

EOEA - Executive Office of Elder Affairs, <http://www.mass.gov/elders>

EOHHS - Executive Office of Health and Human Services, <http://www.mass.gov/eohhs>

EOLWD - Executive Office of Labor and Workforce Development,
<http://www.mass.gov/executive-office-of-labor-and-workforce-development>

EPSDT - Early and Periodic Screening, Diagnosis and Treatment

F-G

FCSN/FEDERATION - The Federation for Children with Special Needs, <http://www.fcsn.org/>

FSP - Family Support Plan

GAL - Guardian Ad Litem

H-I

HCBSW - Home and Community Based Services Waiver

HHA - Home Health Aide

HIPAA - Health Insurance Portability and Accountability Act of 1996

HMO - Health Maintenance Organization

HOH - Hard of Hearing

HRO - Human Rights Officer

HUD - Department of Housing and Urban Development, <https://www.hud.gov/>

ICAP - Inventory for Client and Agency Planning

ICF/MR - Intermediate Care Facility for Individuals with DD

ICI - Institute for Community Inclusion, <http://www.communityinclusion.org/>

ID - Intellectual Disability

IDEA - Individuals with Disabilities Education Act

IEP - Individualized Education Plan

ILC - Independent Living Center

ISP - Individual Support Plan

ITP - Individual Transition Plan

J-L

LEA - Local Education Authority

LHA - Local Housing Authority

M

MAAPS - Massachusetts Association of 766 - Approved Private Schools, <http://www.spedschools.com/>

M.A.S.S. - Massachusetts Advocates Standing

Strong, <http://www.communitygateway.org/local/mass.htm>

MASSCAP - Massachusetts Comprehensive Assessment Process

MassHealth - Office of Medicaid, MassHealth, <http://mass.gov/masshealth>

MBTA - Massachusetts Bay Transportation Authority, <http://www.mbta.com/>

MCB - Massachusetts Commission for the Blind, <http://www.mass.gov/mcb/>

MCDDH - Massachusetts Commission for the Deaf and Hard of Hearing, <http://www.mass.gov/mcdhh/>

MCO – Managed Care Organization

MDDC - Massachusetts Developmental Disabilities Council, <http://www.mass.gov/mddc/>

MFOFC – Massachusetts Families Organizing for Change, www.mfofc.org

MI - Mental Illness

MRC - Massachusetts Rehabilitation Commission, <http://www.mass.gov/mrc/>

MS - Multiple Sclerosis

N-O

ORI - Office for Refugees and Immigrants, <http://mass.gov/ori>

OT - Occupational Therapy

P-Q

PAC (also referred to as SEPAC)- Special Education Parent Advisory Council

PASRR - PreAdmission Screening and Resident Review

PCA - Personal Care Attendant

PCP - Person Centered Planning

PDD - Pervasive Developmental Disorder

PDD, NOS - Pervasive Developmental Disorder, Not Otherwise Specified

POC- Plan of Care

PT - Physical Therapy

PTSD - Post Traumatic Stress Disorder

R

RAC - Regional Advisory Council

RFP - Request for Proposal

RFR - Request for Response

RTA - Regional Transit Authority

S

SAC - Statewide Advisory Council

SHIP - Statewide Head Injury Program (MRC), <http://www.mass.gov/mrc/ship>

SNF - Skilled Nursing Facility

SpEd - Special Education

SSA - Social Security Administration, <http://www.ssa.gov/>

SSDI - Supplemental Security Disability Income

SSI - Supplemental Security Income, <http://www.ssa.gov/pgm/ssi.htm>

T

TASH - The Association for Persons with Severe Handicaps, <http://www.tash.org/>

U-V

UCEDD - University Centers for Excellence in Developmental Disabilities

UCPA - United Cerebral Palsy, <http://www.ucp.org>

VG - Virtual Gateway

VNA - Visiting Nurses Association

W-Z

WIC-The Massachusetts Woman, Infants, and Children Supplemental Nutrition Program, <http://www.mass.gov/wic>

For More Comprehensive List:

<http://www.mass.gov/eohhs/gov/departments/dds/developmental-services-acronyms.html>

GLOSSARY OF TERMS

504 PLAN – A 504 Plan helps a child with special health care needs to fully participate in school. Usually, a 504 Plan is used by a general education student who is **not** eligible for special education services provided through an IEP. A 504 Plan lists accommodations related to the child's disability and required by the child so that he or she may participate in the general classroom setting and educational programs.

ABLE ACCOUNT – With the Achieving a Better Life Experience (ABLE) Act, saving and investing for disability-related expenses including housing, healthcare, and transportation has been made easier. Americans with disabilities now have the opportunity to save and invest in a tax-advantaged account for short- and long-term expenses. An ABLE account is a smart way to save that supplements, rather than replaces Medicaid and SSI benefits.

ACCOUNTABLE CARE ORGANIZATION (ACO) - EOHHS defines ACOs as “provider-led organizations that coordinate care, have an enhanced role for primary care, and are rewarded for value – better cost and outcomes – not volume.” The ACO plan would continue to rely on Medicaid Managed Care Organizations (MCOs) to pay claims and work with ACO providers to improve care delivery.

ADULT FOSTER/FAMILY CARE (AFC) – AFC is a MassHealth program for elderly adults and adults with disabilities who cannot live alone safely. AFC adults live with trained, paid caregivers who provide daily care. Caregivers may be family members (except legally responsible relatives), or non-family members.

AGE OF MAJORITY - When a young person turns 18, that individual is deemed to be of full legal capacity, unless determined incapacitated for reasons other than age. For young people with disabilities approaching this milestone, it is time to consider how best to support them in their decision-making.

AGENCY PAID STAFF AND SUPPORT WORKER - Support workers who have been hired by the provider and are on the provider payroll. This includes respite workers.

AGENCY WITH CHOICE (AWC) – A self-directed model of services in which provider agencies agree to hire individual staff workers that an individual or family choose, to provide services to the person requiring assistance. The individual worker becomes an employee of the provider agency and the agency agrees to help individuals and families train and manage the staff members.

AN ACT RELATIVE TO INSURANCE COVERAGE FOR AUTISM (ARICA) - Effective in Massachusetts on January 1, 2011, this law requires that insured health plans cover “medically necessary” services for the diagnosis and treatment of autism spectrum disorders (ASD) as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM V).

AREA DIRECTOR (AD) - A DDS manager who oversees the administration of services and supports for those eligible individuals and families tied to that Area Office based on the defined catchment areas. The DDS Area Director is responsible for ensuring continuity of services to individuals and families.

AREA OFFICE (AO) - A DDS office that is geographically located to provide local services in a specific service area within the state. There are 23 Area Offices statewide.

AUTISM SPECTRUM DISORDER (ASD) - *Autism Spectrum Disorder* (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges.

AUTISM SUPPORT CENTERS - Autism Support Centers provide an array of information and referral services, resources and supports to children and adults with autism spectrum disorders. The array of services and supports to families includes information and referral, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events, among other activities.

CHAPTER 688/ TURNING 22 - Chapter 688 of the Acts of 1983, now G.L. ch. 71B, is a law to provide a two-year planning process for young adults with disabilities whose entitlement to special education will end at the age of 22 or at the time of receiving a high school diploma, whichever comes first. The law creates a single point of entry into the adult human service system. Only the local school system can make a 688 referral while the student is still in school.

CHILDREN'S AUTISM WAIVER PROGRAM - The Autism Waiver Program at the Department of Developmental Services Autism Division serves children, birth through age 8, with an autism spectrum disorder who meet the eligibility criteria. The Autism Waiver allows children to receive Expanded Habilitation, Education, in-home services and supports, such as Applied Behavioral Analysis (ABA) and Floor Time, for a total of up to 3 years. <https://www.mass.gov/service-details/dds-autism-waiver-service-program-overview>

CHILDREN'S BEHAVIORAL HEALTH INITIATIVE (CBHI) – Mission is to ensure that children with MassHealth coverage who have significant behavioral, emotional and mental health needs and their families get the services they need for success in home, school, community, and throughout life. Through CBHI, MassHealth requires primary care providers to offer standardized behavioral health screenings at well child visits, mental health clinicians to use a standardized behavioral health assessment tool, and provides new or enhanced home and community-based behavioral health services. <https://www.mass.gov/masshealth-childrens-behavioral-health-initiative>

CITIZEN ADVISORY BOARD (CAB) - DDS Citizen Advisory Boards play a vital role on both a Regional and Area basis in the Department's planning, policy formulation, program development and evaluation. The CABs meet regularly with DDS staff to become informed of DDS initiatives and voice their opinions and ideas about the quality of programs that support individuals with disabilities and their families.

COMMUNITY INCLUSION - Community Inclusion can be defined as attitudes, approaches and strategies that ensure that everyone is included as valued members of their community and have the right to pursue their own goals and dreams. People are not only “in their Community” but “of their Community”.

COMMUNITY PARTNERS -Community Partners are designated community-based health care and human service organizations that will partner with the MassHealth Accountable Care Organizations (ACOs) to integrate and improve health care outcomes for MassHealth members with complex long term medical and/or behavioral health needs, including individuals with disabilities, mental illness, substance misuse disorders and co-occurring disorders. <https://www.mass.gov/guides/masshealth-community-partners-cp-program>

COMMUNITY SYSTEMS DIRECTOR – The Community Systems Director is a DDS manager who acts on behalf of the Regional Director to implement DDS statewide/Regional initiatives in service delivery. The Community Systems Director provides guidance, support and oversight of various specialized programs and services.

CONSERVATOR – A person appointed by the court to manage the estate of a protected person.

CONSUMER AND CAREGIVER ASSESSMENT (CCA) - A DDS tool that assesses the resources and supports that currently are in place for the individual and provides information to assist in evaluating the capacity of the caregivers.

CRIMINAL OFFENDER RECORD INFORMATION (CORI) - Information regulated by the Criminal History Systems Board and maintained by the Board of Probation regarding the criminal histories of persons within the Massachusetts Court system.

DEPARTMENT OF CHILDREN AND FAMILIES (DCF) - The Department of Children and Families (DCF) is the state agency in Massachusetts that works with families and communities to keep children safe from abuse and neglect. In most cases, DCF is able to provide supports and services in order for children to continue living with parents or family members. When necessary, DCF provides foster care or finds new permanent families for children through kinship, guardianship or adoption. <https://www.mass.gov/orgs/massachusetts-department-of-children-families>

DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION PROGRAM (DESE) - The Massachusetts Department of Elementary and Secondary Education (DESE) is the state agency responsible for licensing educators, distributing state and federal education money, helping districts implement learning standards, overseeing statewide standardized tests, monitoring schools and districts, and convening school districts and individuals to share best practices. <http://www.doe.mass.edu/>

DESE/DDS PROGRAM - A statewide partnership program that is designed to provide intensive in-home and community based therapeutic supports to students with intellectual disabilities ages 6 to 22 years. The DESE/DDS Program is administered by the Department of Developmental Services with funding from the Department of Elementary and Secondary Education.

DEPARTMENT OF MENTAL HEALTH (DMH) - The Department of Mental Health, as the State Mental Health Authority, assures and provides access to services and supports to meet the mental health needs of individuals of all ages; enabling them to live, work and participate in their communities. <https://www.mass.gov/orgs/massachusetts-department-of-mental-health>

DEPARTMENT OF PUBLIC HEALTH (DPH) - The Massachusetts Department of Public Health (DPH) promotes the health and well-being of all residents by ensuring access to high-quality public health and healthcare services, and by focusing on prevention, wellness and health equity in all people. DPH also has the responsibility for administering and overseeing the statewide system of Early Intervention services for children from birth up to their third birthday. <https://www.mass.gov/orgs/department-of-public-health>

DURABLE POWER OF ATTORNEY (POA) - In accordance with G.L. ch. 190B, Section 5-501, a legal document that enables an individual (called the "principal" in the **power of attorney** document) to appoint an "agent," such as a trusted relative or friend, to handle specific health, legal and financial responsibilities.

EXECUTIVE OFFICE OF ELDER AFFAIRS (EOEA) - The Executive Office of Elder Affairs (EOEA) promotes the independence, empowerment, and well-being of older adults, individuals with disabilities and their caregivers. The EOEA and the Aging Network of Councils on Aging (COAs), Aging Services Access Points (ASAPs), Area Agencies on Aging (AAAs) and Aging and Disability Resource Consortia (ADRCs) have an extensive array of programs and services to offer based on an assessment of individual/family needs. <https://www.mass.gov/orgs/executive-office-of-elder-affairs>

FAMILY IDENTIFIED STAFF - Family independently recruits and hires self-identified staff for support (respite, skills training, etc.).

FAMILY SUPPORT CENTERS – DDS Family Support Centers offer a wide range of supports and services to individuals with disabilities and their families across the lifespan. These include information and referral, service navigation, support groups, parent networking, family trainings, social/recreational activities and flexible funding allocations, etc. A listing of these Centers can be found in the Statewide Family Support Directory at www.mass.gov/dds)

FAMILY SUPPORT PLAN (FSP) – A planning tool used by DDS funded Family Support Providers with families that identifies and records mutually agreed upon needs and goals.

FAMILY SUPPORT PROVIDERS – Agencies that are contracted by DDS to provide a wide range of family support services, which could include Family Support Centers, In-home and community supports, Medically Complex and IFFS programs, etc.

FLEXIBLE FUNDING ALLOCATIONS – DDS funding resources made available for the purchase of allowable supports and/or goods and services as outlined in this manual. This funding is designed to supplement benefits available to the individual or family through state or federal assistance.

GENERIC SERVICES - Services offered or available to the public that are common to all and are not restricted to a special category of persons.

HEALTH CARE PROXY (HCP) – A document delegating to an agent the authority to make health care decisions, executed in accordance with the requirements of [M.G.L. ch. 201D]. A legal document that enables an individual to appoint an “agent” such as a trusted relative or friend, to legally make health care decisions on their behalf, when he or she is incapable of making and executing the health care decisions stipulated in the proxy.

INDIVIDUAL EDUCATION PLAN (IEP) - According to state and federal laws, all children who have been found eligible for special education must have an Individualized Education Program (IEP). The IEP is a legally binding written plan that describes what special educational services, accommodations, and related services a child will receive. It must be reviewed every year. An IEP is developed by a team of people at the school and includes the parent as an integral part of the IEP Team.

INDIVIDUAL SUPPORT PLAN (ISP) – A written plan of services and goals for a DDS eligible individual who is age 22 or older which is developed, implemented, reviewed, and modified according to the requirements of the Department’s regulations.

INDIVIDUAL TRANSITION PLAN (ITP) – An individualized plan required by Chapter 688 to be completed by the lead state agency (Transitional Agency) to identify beneficial services at completion of educational entitlement.

INTELLECTUAL DISABILITY (ID) - Intellectual Disability means, consistent with the standard contained in the 11th edition of the American Association of Intellectual Disabilities: Definition, Classification, and Systems of Supports (2010), “significantly sub-average intellectual functioning existing concurrently with and related to significant limitations in adaptive functioning. Intellectual Disability originates before 18 years of age. . . . The determination of the presence or absence of Intellectual Disability requires that exercise of clinical judgment.”

INVENTORY FOR CLIENT AND AGENCY PLANNING (ICAP) – A standardized tool that assesses the individual’s skills and adaptive functioning for service planning.

LANGUAGE ACCESS PLAN (LAP) - The Language Access Plan affirms the Department of Developmental Services commitment that all individuals and their families have universal access to the Department's services, programs and activities although they may be limited in their English language proficiency.

LEGAL GUARDIAN (adult) – When a child reaches age 18 a parent can apply for guardianship, if appropriate, to be able to make legal decisions on behalf of the adult child. A guardian is a person appointed by the Probate Court to assume some decision making responsibilities for an individual who is unable to make decisions for him or herself. The guardian is the legal authority and responsible to care for the person and property of another person.

MASSACHUSETTS COMMISSION FOR THE BLIND (MCB) – MCB provides the highest quality rehabilitation and social services to Massachusetts residents who are blind, leading to their independence and full community participation. <https://www.mass.gov/orgs/massachusetts-commission-for-the-blind>

MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING (MCDHH) – MCDHH provides accessible communication, education, and advocacy to consumers and private and public entities so that programs, services, and opportunities throughout Massachusetts are fully accessible to persons who are deaf and hard of hearing. <https://www.mass.gov/orgs/massachusetts-commission-for-the-deaf-and-hard-of-hearing>

MASSACHUSETTS COMPREHENSIVE ASSESSMENT PROCESS (MASSCAP) - The Inventory For Client and Agency Planning (ICAP) and the Consumer and Caregiver Assessment, (CCA) together constitute the **MASSCAP**, an assessment tool used to help determine the need and prioritization for adult services. Used together with the exercise of professional judgement.

MASSACHUSETTS REHABILITATION COMMISSION (MRC) – The Massachusetts Rehabilitation Commission (MRC) helps individuals with disabilities to live and work independently. MRC is responsible for Vocational Rehabilitation, Community Living and eligibility determination for the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) federal benefits programs. <https://www.mass.gov/orgs/massachusetts-rehabilitation-commission>

MASSACHUSETTS SIBLING SUPPORT NETWORK (MSSN) - The MSSN is committed to supporting siblings (brothers and sisters) of people with disabilities in the following ways: creating welcoming communities for siblings across the lifespan; improving the range and availability of sibling support services; and providing education about sibling-related issues.

MASSHEALTH – In Massachusetts, Medicaid and the Children’s Health Insurance Program (CHIP) are combined into one program called MassHealth. MassHealth members may be able to get doctors visits, prescription drugs, hospital stays, and many other important services. MassHealth can be a primary or secondary insurer for children and adults with disabilities, and provides a wide range of short- and long-term services and supports. <https://www.mass.gov/topics/masshealth>

MEDICARE – Medicare is the federal health insurance program for people 65 years or older and for certain younger people with disabilities.

NAVIGATOR – A provider staff who assists families in caring for their family member at home by providing individualized guidance, support and problem solving assistance, as well as helps families access and coordinate potential community resources and services.

OFFICE OF CHILD ADVOCATE (OCA) - The OCA works to ensure Massachusetts state agencies provide children with quality services and protect them from harm. They work with families, legislators, social workers, and other professionals to improve state services for children and families. Anyone with concerns about a child or youth receiving services from a state agency can contact the OCA. Family Support and DDS staff can refer to Section X (F) to understand their specific

responsibilities related to the OCA reporting. <https://www.mass.gov/orgs/office-of-the-child-advocate>

PERSONAL CARE ATTENDANT (PCA) - The Personal Care Attendant (PCA) program is delivered by MassHealth to provide funds for people with disabilities to hire Personal Care Attendants to assist with activities of daily living such as bathing, dressing, eating, toileting, etc. <https://www.mass.gov/service-details/become-a-pca-today>

PERSON-CENTERED PLANNING (PCP) - Person-Centered Planning is a set of approaches designed to assist someone to **plan** their life and supports. It is used most often as a life **planning** model to enable individuals with disabilities or others requiring support to increase their personal self-determination and improve their own independence.

PRADER WILLI SYNDROME - Consistent with National Institute of Health, Prader-Willi Syndrome is a complex genetic condition that affects many parts of the body. In infancy, this condition is characterized by weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development. Beginning in childhood, affected individuals develop an insatiable appetite, which leads to chronic overeating (hyperphagia) and obesity. <https://ghr.nlm.nih.gov/condition/prader-willi-syndrome>

REGIONAL DIRECTOR (RD) - A DDS manager who oversees the administration and management of supports to those Area Offices within the region's catchment area. DDS has four defined regions; Central West, Northeast, Southeast, and Metro.

REGIONAL FAMILY SUPPORT DIRECTOR - Person who provides direction, oversight, and support for the planning and delivery of Family Support Services provided within that DDS region.

REGIONAL OFFICE- Each Area Office reports to one of four geographically located Regional Offices. The Regional Office provides management of the Area Offices and performs Regional functions such as: intake and eligibility determination, survey and certification of service providers, procurement and contracts, legal and administration, abuse and mistreatment investigations.

REPRESENTATIVE PAYEE - In cases in which an individual is not capable of managing his or her own Social Security or Supplemental Security Income (SSI) payments benefits, Social Security appoints a person who manages the payments on behalf of the beneficiary. <https://www.ssa.gov/payee/>

RESPIRE - Short term temporary relief to families caring for individuals living at home. Respite can be provided in the individual's home, in the community, or in a variety of out-of-home settings. Respite reduces family/caregiver stress and helps to preserve the family unit, supports family stability and prevents lengthy and costly out-of-home placements.

REWARDING WORK RESPITE DIRECTORY - The Massachusetts Respite Directory is a partnership between Rewarding Work and the Department of Developmental Services to assist families in finding respite workers when they are needed. The Directory provides up-to-date names and contact information of people who can provide respite on either a full- or part-time basis, their experience and availability. The website also enables individuals and families to post a job listing to recruit staff. www.rewardingwork.org (DDS Access code: ddsconnect)

SECTION 8 HOUSING ASSISTANCE - The Section 8 Housing Choice Voucher Program is the federal government's major program for assisting very low income families, the elderly, and the disabled to rent decent, safe and sanitary housing in the private market. The participant is free to choose any housing that meets the requirements of the program and is not limited to units located in subsidized housing projects. <http://www.section8listmass.org/>

SELF-DETERMINATION - Self-Determination is the concept of having control in one's life and to make choices based on preferences, beliefs and the ability to influence one's future.

SELF-DIRECTION – Self-Direction is a method of service delivery that gives individuals and their families control over their services and the staff who support them. Self-direction offers individuals more control and flexibility over their services but also more responsibility than in a traditional provider operated service. Self-Directed options include Participant Directed Programs and Agency With Choice.

SERVICE COORDINATOR - Staff designated by the local DDS Area Office to arrange, coordinate, monitor services or supports provided, purchased, or arranged by the Department for a particular individual.

SERVICE NAVIGATION - Service Navigation is the provision of comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving, and help them navigate the service system. This service is available to families of both children and adults. The level of involvement with each family will vary based on the needs of the individual and family. Some families use this on more of a short-term, time-limited basis, (*Short-Term Navigation*) and for others this is provided on an extended basis to help support them in caring for their family member (*Extended Navigation*).

SHARED LIVING – The Shared Living Support Model places an individual into a care providers' home under the supervision of a qualified provider agency. The agency recruits, screens, trains and delivers on-going support to caregivers who meet the needs of the individuals based on a person centered plan.

SMITH MAGENIS SYNDROME – means, consistent with the definition of the National Institute of Health, a neurodevelopmental disorder characterized by a well-defined pattern of anomalies typically due to a common deletion in chromosome 17 found by genetic testing.

SOCIAL CAPITAL – Social Capital refers to the collective value of “social networks”, (who people know) and the inclinations that arise from these networks to do things for each other (the norms of reciprocity). These connections increase individual well-being and opportunities by linking people more strongly to their local community and to larger societal resources.

SOCIAL SECURITY DISABILITY INCOME (SSDI) – SSDI pays benefits to individuals and certain members of their family if they are "insured," meaning that they worked long enough and paid Social Security taxes. <https://www.ssa.gov/disability/>

STATEWIDE FAMILY SUPPORT COUNCIL - The Statewide Family Support Council, comprised of family members from across the state, provides a substantive and ongoing vehicle for input and consultation to the DDS Commissioner on family support services, practices, policies, and needs.

SUPPLEMENTAL SECURITY INCOME (SSI) – The SSI program provides monthly income to people who are age 65 or older, or are blind or disabled, and have limited income and financial resources. An individual's financial resources and income may impact benefits and eligibility. Work is not a requirement of this program.

SUPPORT BROKER- A DDS Support Broker provides specialized coordination for individuals enrolled in the Department's Participant Directed Program. The Broker works with the individual, guardian, family, friends and “circle of support” to identify a person's needs, wants and goals to begin planning for their Self Directed services. The Support Broker assists in translating the person's vision into a customized service plan and individual budget and supports the individual through the process.

SUPPORT SERVICES QUALIFYING LIST (SSQUAL) – These include an array of in-home skills training and community support services funded by DDS and delivered by qualified providers. Many of these services are included in the Department's Home and Community-Based Waiver Programs.

TRANSITION PLANNING FORM (TPF) – The TPF is a section of the Individual Education Plan (IEP) that outlines transition goals and services for students age 14 and older. The TPF is the template for mapping out long-term adult outcomes from which annual goals and objectives are defined and incorporated into the main body of the IEP.

WAIVER SERVICES – The Department of Developmental Services (DDS) Home and Community-Based Services Waivers are a way for individuals to receive services in their home instead of an institution. These Waivers are a federal state partnership. They are run by the Commonwealth of Massachusetts through MassHealth (Medicaid) which pays for health care and services in the home for individuals living in Massachusetts who have limited income. <https://www.mass.gov/dds-home-and-community-based-services-waivers>

Massachusetts Department of Developmental Services

Section: I - Guiding Principles of Family Support

THE GOALS AND PRINCIPLES OF FAMILY SUPPORT

The primary goal of family support is to provide a wide array of options to individuals with disabilities and their families that enable them to stay together and live in a nurturing environment, maintain relationships with families and loved ones and be welcomed, contributing members in their home communities. DDS provides this through its Family Support Centers, Autism Support Centers, Medically Complex Programs, Intensive Flexible Family Supports (IFFS), and Family Leadership programs. Families, therefore, should have access to supports that are necessary and appropriate to help the family member with a disability to remain in the home.

Families and individuals with a disability are most knowledgeable regarding their strengths, competencies, capacities, and needs. Family members and the individual themselves are in the best position to know what will help them have a fulfilling life with the most independence possible. Respect for families and individuals and recognition of each family's expertise, diversity, unique characteristics, and cultural and spiritual values are the foundation of family support.

Individuals with disabilities and their families can enrich the lives of others in many ways. Family support promotes the development and growth of relationships and natural support networks within the community. It encourages families in their efforts to promote the inclusion of their family members with disabilities in education, recreation, and all other aspects of community life.

People with disabilities have personal preferences and needs to live, learn, grow, and develop relationships. They have abilities, competencies, and dreams, and should be supported and encouraged to pursue their personal desires. Family support responds to family-identified needs and direct input from individuals with disabilities. It offers families and individuals the opportunity to exercise control and direction over the supports that are available to them.

Family Support helps families stay together by:

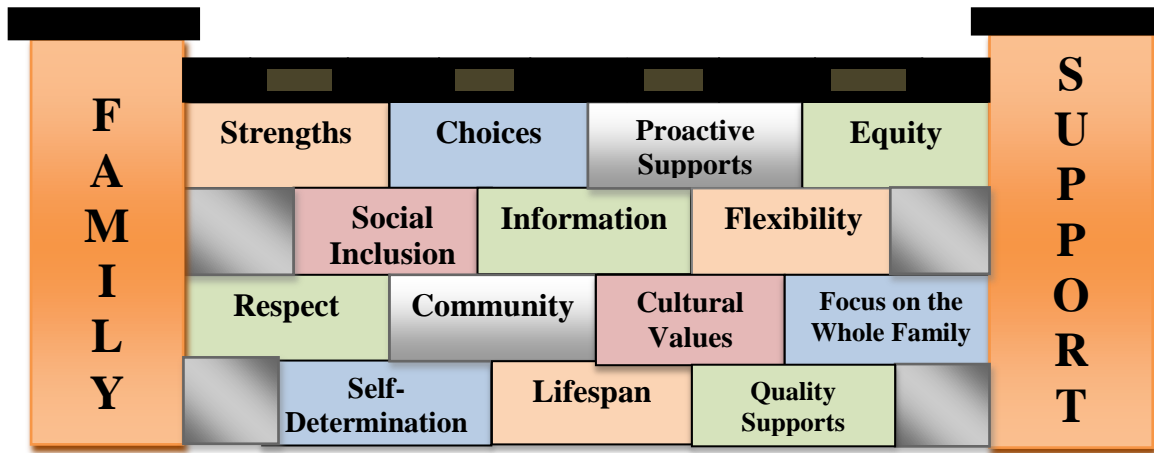
- Developing families' natural capacity to address the needs of family members across the lifespan
- Offering additional supports such as staff resources, goods and services, and financial assistance
- Enhancing the capacity of communities to value and support people with disabilities and their families
- Promoting self-determination values and self-directed options

The Principles that Guide Family Support:

- Recognize that individuals with disabilities and their families are the primary decision makers about their lives
- Focus on the whole family and recognize that benefits to the individual with a disability also benefit the whole family
- Offer flexible options that are responsive to families unique needs, strengths and cultural values
- Afford opportunities for increasing individual self-direction and family control in the planning, implementation, and evaluation of family support services.
- Support the development of the family's natural capacities for innovation, initiative, and leadership.

- Provide proactive supports to encourage family independence and capacity-building
- Build on existing natural and community supports and maximize the use of generic resources
- Respond to the specific ethnic, cultural and linguistic needs of families
- Respect individuals with disabilities and their families as valued members of the community
- Ensure equitable and fair availability of services throughout the State

These principles serve as the foundation for how family support services are delivered and how DDS and provider staff engage with families.



Building A Foundation

"The future belongs to those who believe in the beauty of their dreams."
Eleanor Roosevelt

COMMUNITY MEMBERSHIP

The Department of Developmental Services is committed to enhancing opportunities for individuals with disabilities to become fully engaged members of the community. Family Supports should actively work to build bridges to ensure that people are not just “in” the community but “of” it in ways that result in a true sense of belonging.

“Building Bridges to Inclusive Communities”



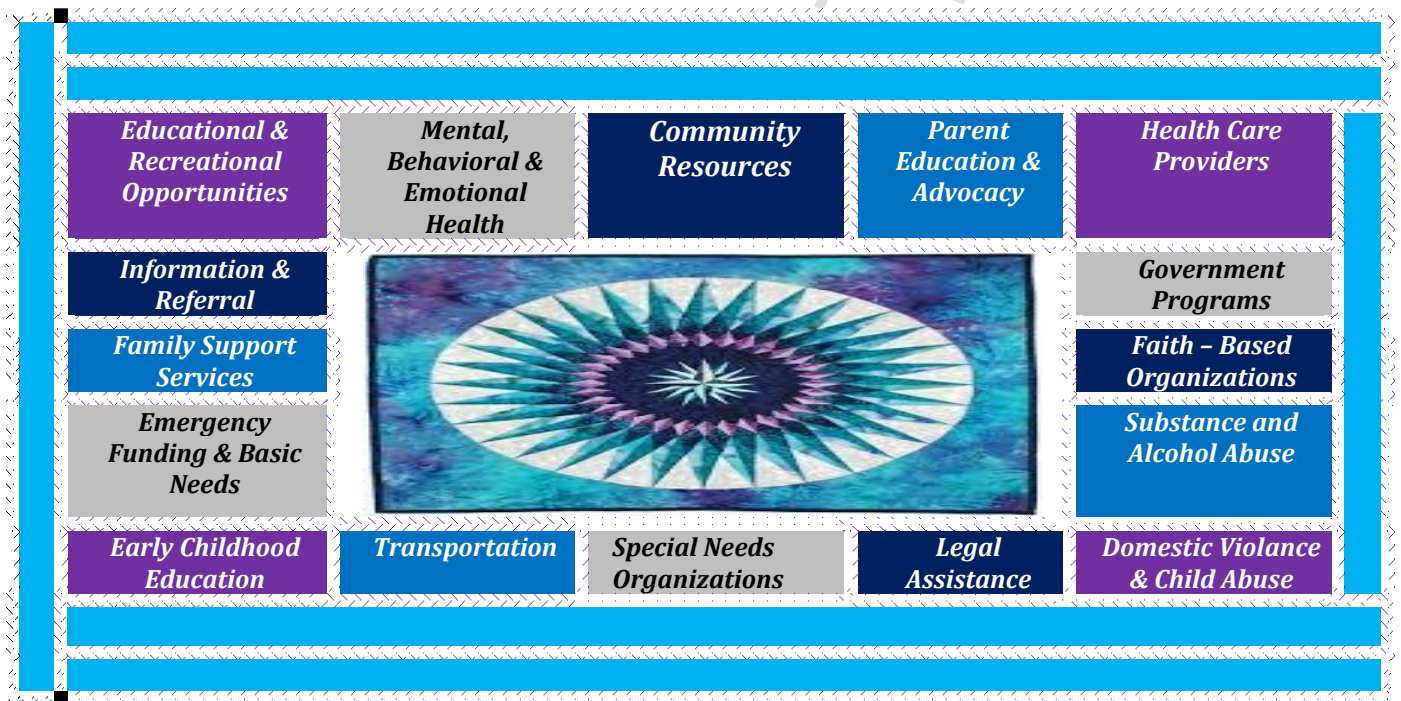
For “**STRATEGIES to Consider for Connecting People With & Without Disabilities**”, refer to Section XIV (D) in this Manual.

MAXIMIZING COMMUNITY RESOURCES

One of the Guiding Principles of Family Support is to build on existing natural supports and maximize the use of resources and services that are generally available in the community. There are several important reasons why it can be very beneficial to explore and utilize these resources:

1. Given the varied needs of individuals with disabilities and their families, developing and using a combination of different kinds of support besides state-funded services enables people to build a more inclusive and quality life in their community.
2. The use of community-based resources helps to maximize DDS resources to reach more people and supplement services to those who need additional supports.
3. The utilization of generic resources often builds community connections and relationships not only for the individuals served but also for those who help them navigate these resources.
4. There are very unique resources in local communities/neighborhoods which can address some basic emergency needs such as clothing, food, and shelter, etc. that many families and navigators may not know about.
5. Some generic services are very specialized and address issues or needs that governmental agencies may not have the expertise and/or capacity, such as educational advocacy, substance and alcohol abuse, domestic violence, hobby clubs and other recreational opportunities, etc. The Community Quilt below illustrates a small sampling of these resources.

Community Quilt



Massachusetts Department of Developmental Services

Section: II - Overview of Family Support Services

A. Background

The Department of Developmental Services (DDS) has been providing a wide array of flexible family support services since 1995 to children and adults who are eligible for services from DDS living at home with their families. Given the national trends in shifting from a legacy of institutional care to community living and membership, Massachusetts has been at the forefront in its commitment to supporting individuals with intellectual and developmental disabilities and their families in leading quality lives in their local communities.

In 2010, DDS redesigned its family support system. The Department's strategic plan included the procurement of a constellation of designated family support programs that would be consistently available throughout the state and readily accessible to families. Integral to this effort is the adoption of a lifespan approach in order to be responsive to the needs and challenges faced by individuals and families at important transition stages in their lives.

DDS uses multiple approaches, both formal and informal, to seek input and guidance from individuals with intellectual disabilities and their families in order to help assess the Department's current system of family support services, and help inform policy development and future directions.* DDS has partnered on different initiatives with family members and family support providers over the years to strengthen the information, resources, and assistance provided to families to assist them in their caregiving role. In 2012 DDS issued a report, *"In Their Own Words: The Need for Family Support Services,"* which summarized input from families about their experiences, needs, the types of assistance and supports they find most important and helpful to them, and the overall benefits of providing supports to families to help avoid more costly out-of-home residential placements. Families identified the need for respite, easier access to information along with help navigating the service system, flexible funding resources, and increased opportunities for social and recreational opportunities for their family members with a disability, as the most important and beneficial types of assistance. This report is available on the DDS web-site at: www.mass.gov/dds.

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

* These activities support the Department's response to the requirements of Chapter 171 of the Acts of 2002, "An Act Providing Support to Individuals with Disabilities and Their Families," which results in the development of a Plan for Family Support that is submitted to the legislature annually.

B. Overview of Family Support

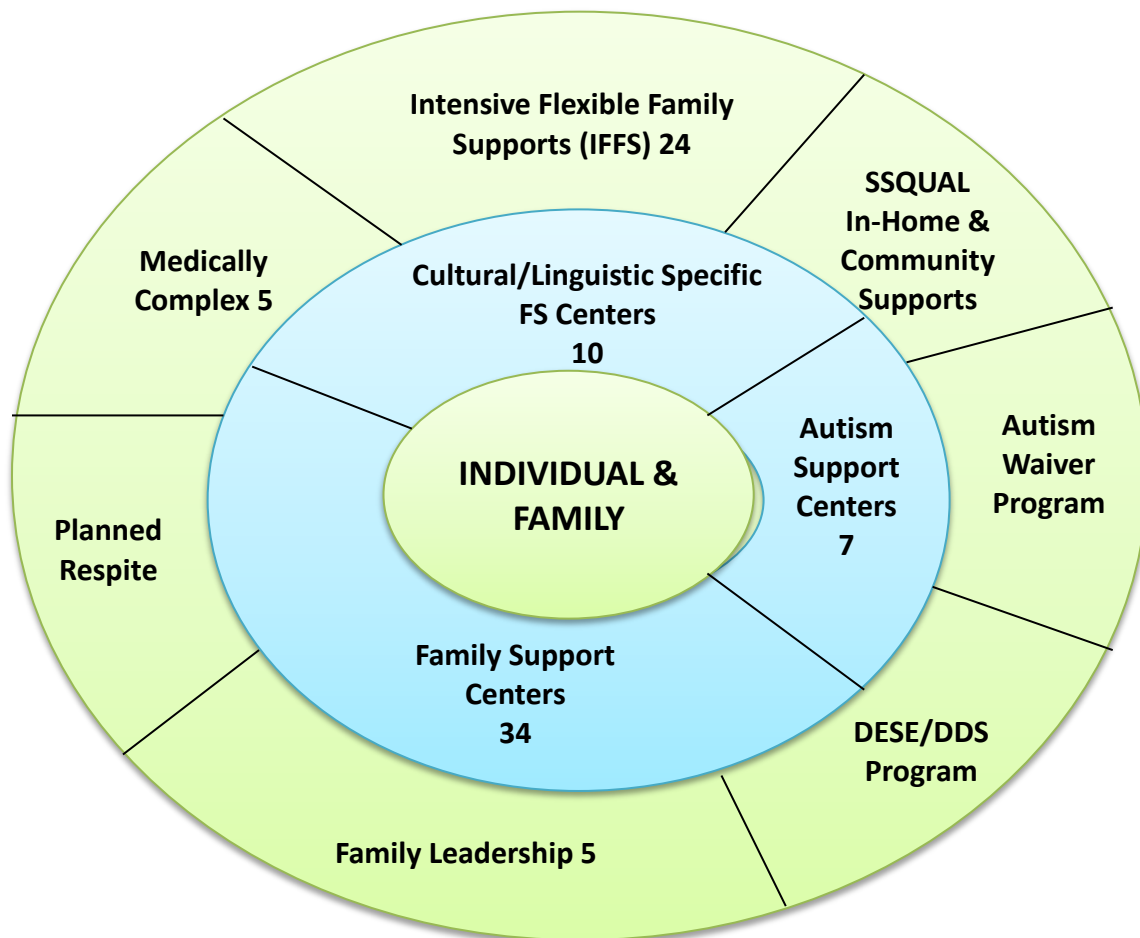
The primary goal of family support is to provide a variety of options to individuals with disabilities and their families that enable them to stay together and to be welcomed, contributing members in their home communities. The DDS Family Support system is based on the principle that individuals and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

C. General Family Support Center Services

These core family support center services are generally available to all families who connect with any of the three types of family support centers. Families are sent a ‘welcome flier’ with information about the Family and Autism Support Centers in their geographic area at the time their son or daughter is found eligible for services. If families are not already connected to a local Center, it gives them the information to make that contact. This notice is available in multiple languages to be responsive to families for whom English is not their primary language.

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

The DDS funded Family Support, Cultural/Linguistic-Specific, and Autism Support Centers provide Information and Referral services to families of children and adults within their geographic area. This includes assisting families to identify resources and service options available in their local communities, to learn about other financial and/or state services for which families may be eligible, and to provide guidance on how to navigate the service system. The Centers use a variety of approaches to disseminate information to families, including email, list-serves, web-sites, on-line newsletters and training calendars, webinars, and social media, as well as creating and maintaining a “library” of resources. All of these Centers are expected to engage in a variety of outreach activities to connect with families in different venues who may benefit from their information and resource services, including early intervention programs, local school systems, health care providers and through other community based organizations.



This diagram broadly reflects the Department's family support system with the individual and their family at the center. The inner circle includes the three types of centers which can be accessed directly by families, with reference to the number of programs currently available in the state. The outer circle represents specialized family support program or services that have defined eligibility criteria and referral protocols. (Can be found in this manual.)

DDS funded Family Support and Autism Support Centers provide an array of educational events and trainings on relevant topics of interest to families of both children and adults. These Centers are required to offer a minimum of six training events per year, with many offering additional training opportunities. Leadership development is also promoted through the Centers by facilitating parent networking and mentoring, sponsoring parent support groups and one-to-one parent connections, grandparent support groups, and sibling support opportunities, and referrals to Family Leadership Programs funded by DDS.

DDS funds at least one **Family Support Center** in each Area Office catchment area (some have more) across the state intended to establish a local community presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults eligible for DDS services. Centers are expected to develop strong local affiliations and partnerships with other state and community agencies, become experts in generic resources and services, and work to maximize natural supports. Services provided include: information and referral, support groups, family trainings, parent networking and mentoring, facilitation of social/recreational events, among other activities. Centers also provide Service Navigation that includes individualized and comprehensive information, guidance, and support to families to address their needs, connect them

to potential resources, assist with problem-solving and help them navigate the service system. Centers administer flexible funding to families who are prioritized to receive an individual allocation which can be used flexibly by families to purchase allowable services and goods as defined in the Department's updated Family Support Program Manual and Guidelines. (See Section VII)

Cultural/Linguistic-Specific Family Support Centers are designed to respond to the unique needs of specific cultural and linguistic family groups in specified areas or regions of the State. English is not the primary language for many of these families, and as a result they face linguistic barriers in accessing services and require more individualized and specialized assistance to learn about and access the service system. In addition, these ten Centers offer some of the same services as the Family Support Centers described above.

Autism Support Centers provide an array of information and referral services, resources, and supports to children with autism spectrum disorders (ASD) and over the past several years, their focus has expanded to support adults with ASD who do not have an intellectual disability and their families. The array of services and supports includes, but is not limited to, information and referral, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events. There are seven Autism Support Centers spread across the state.

D. Specialized Family Support Programs

Intensive Family Support Services and Medically Complex Programs provide more comprehensive and intensive navigation services to respond to the unique, complex and multiple challenges of individuals and their families.

Intensive Flexible Family Supports (IFFS) Programs are designed to help families who are experiencing severe stress which can lead to the child being at-risk of an out-of-home placement. Intensive case management services are provided to help families integrate the variety of available resources to support their family member in crisis, and flexible funding to purchase additional supports or goods. These program services, originally designed to assist families of children between the ages of 3 and 18, have been expanded to age 22 to be responsive to the emerging needs of the 18 to 22 age group of young adults living with their families and transitioning from school to adult life.

Medically Complex Programs support families who are caring for children/young adults up to the age of 25, with significant cognitive, physical, and complex health care needs who are living at home. Intensive case management services are provided to help families integrate the variety of resources and supports they are receiving. These programs also offer flexible funding to assist the family in the purchase of additional supports and goods not covered by health insurance. These five programs complement and are supplemental to other MassHealth State plan and third party insurers.

E. Family Leadership Programs

DDS funds five Regional Family Leadership programs and partners with Massachusetts Families Organizing for Change (MFOFC) to provide education, leadership training, and mentoring for families of children and adults with disabilities. This training and mentoring is developed and provided by families who have a family member with a disability, an important feature of these programs. A major focus is a Family Leadership Series which occurs across 6-8 days over a several month period. This Series provides information and education about "best practices" and helps families gain knowledge about policy making at the local and state level to assist them in assuming leadership roles in their local community and the disability community.

F. Support Services/Support Services Qualifying List (SSQUAL)

In addition to the services and supports discussed previously, the Department offers a variety of in-home and community support services available to adults and children living at home with their families. These services are delivered by qualified provider agencies. Some of these services are only available to adults, some are for children, and some are for both. Examples include respite in the family home and adult companion services.

Providers are qualified to offer and deliver these services through a Request for Qualification (RFR) process administered by DDS, known as the Support Services Qualifying List (SSQUAL). In delivering these services, qualified providers are responsible for recruiting, training and supervising the staff who provide these services to individuals living with their families. Individuals and families can select providers from the qualified list available in their specific geographic area to deliver the specific services they have requested and need. Some of the agencies qualified to deliver these SSQUAL services are also providers of the Family Support and Autism Support Centers or other Family Support Program services.

Individuals/families who are prioritized to receive a flexible funding allocation from their respective Area Office may also choose to use some or all of this allocation to pay for specific SSQUAL services delivered by a qualified provide. These SSQUAL services are arranged by and contracted by the local Area Office and individuals/families will need to work with their Area Office in accessing these services.

A list of the specific SSQUAL services and their corresponding rates can be found at: <https://www.mass.gov/lists/dds-pos-contracts-information>. Many of these SSQUAL services for adults are included in the Department's Home and Community Based Waiver Programs, and for individuals participating in one of the federal Waiver programs these services are reimbursable through the federal government.

G. Other Family Support Initiatives

The Department continues to address individual and family needs on a consistent basis across the state. The goal is to have a group of designated services that families can expect are generally available in each Region/Area Office. However, Regional and Area Offices also work in partnership with their family support agencies to respond to local and specialized individual and family needs. Some examples of these types of services and initiatives include the following; after-school programs, inclusive social/recreational opportunities, camps, Supported Parenting initiatives, a variety of support groups for dads, grandparents, teens, self-advocates, Sib Shops etc.

Individuals and families should check with their Area Office Service Coordinator to find out which family support options and services are available in their catchment area or region. The Regional Family Support Director is also a resource for information on available services in each region. Many of these specialized resources have limited capacity based on the availability of funding and/or vary depending on the priorities of each area/region.



Wings for Autism® is a program of the Charles River Center in partnership with Massport, TSA and several Airlines. This unique program is designed specifically for families of children with autism to help ease their stress of flying. The picture was taken at one of their events.

Other Family Support Initiatives

Grandparents, Sibling, Parenting
Groups

Inclusive Social
& Recreational
Programs

Self Advocacy
Groups

Afterschool &
Vacation
Programs

Cultural
Outreach and
Support Groups

Massachusetts Department of Developmental Services

Section: III – Relationship Between Family Support Programs & Families

Supporting families across the lifespan is at the heart of the Department of Developmental Services (DDS) family support system. Family support programs are designed to assist individuals and families in developing a vision for a full and quality life and support them throughout their life journey with positive experiences and opportunities. It's essential that the family support provider establish a trusting relationship with families in order to achieve that mission.

Families may initially contact a family support center or another family support program seeking help with a particular situation or issue they are currently confronting or they are simply looking for an answer as to where to begin. Frequently families have had the unfortunate experience of being bounced from one agency to another. It is the Department's goal, in concert with its family support providers, to provide a "welcoming" and comfortable place for families. The expectation is for these programs to help families in problem-solving their immediate issues, but also to develop an ongoing relationship with families as they encounter new issues and transitions across the lifespan.

Family Support Centers should provide each family with a contact person for the family to connect with directly and to establish an on-going relationship. Families should have the option of continuing to work with a familiar staff person who understands the family's culture, language and individual needs and values. This relationship will hopefully enable the family "to take a longer view" and utilize a person-centered planning focus or process.

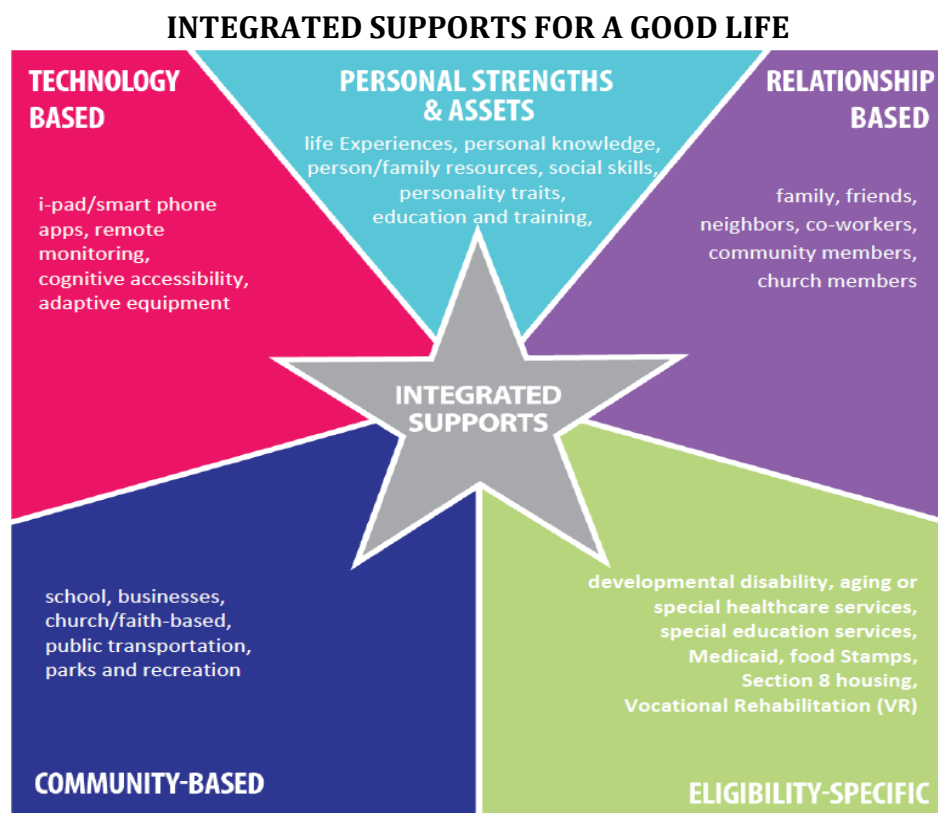
DDS always encourages using a ***person-centered approach***, which simply means that the person being supported is at the center of the conversation, and any plan that is developed is based upon their goals and support needs. Every individual has preferences around what they want in life -- and what they don't want in life -- and these preferences can be communicated in any number of ways, regardless of verbal communication abilities. Families and guardians often play a key role in helping to communicate an individual's wishes.

Any type of planning process that's used should integrate supports that are available through the community, personal relationships, and technology, with the individual's choices and vision at the center of the plan, as described below:

- During any planning process, it's important to identify the natural supports that the individual and family currently have and the needs that such supports satisfy/meet. If a natural support does not fully meet an identified need, the Family Support Provider shall assist the family in exploring the availability of generic and eligibility-specific resources that will help meet their needs.
- Individuals can start learning to be self-determined at an early age by having opportunities to make choices, learn about new places and things, build community connections, develop skills, and learn responsibility. When an individual approaches adulthood, whenever possible, the support offered should lead to increased independence for the individual. The individual's preferences should drive what he/she wants for help, how they wish to be supported and the ways the individual wants to be involved in their community. For people who may not be able to verbally express their preferences, families/guardians can play a pivotal role.
- Any plan should include opportunities for the individual to increase his or her social capital by engaging the person in their local community and supporting the development of relationships

with people with and without disabilities. Staff who provide supports and the family support programs can also play an important role in facilitating community connections and being a bridge builder to tap into social network. **See Section XIV (D) for Strategies to Consider For Connecting People With and Without Disabilities.**

Historically, supporting people with disabilities and their families has revolved around the delivery of supports and services offered by the disability service system in each state. DDS’ goal is to help individuals and families realize that we ALL utilize a variety of supports throughout our daily lives. Individuals and families choose to access an array of integrated supports in order to achieve their vision of a good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based supports; technology; and that take into account the assets and strengths of the individual and family (as illustrated in the Integrated Star below).



- **For more information on this Integrated Star, see Charting the LifeCourse tools under Resources in this section.**

Some families may choose to engage in a more ***formal Person-Centered Planning process***, which typically requires an outside facilitator and participation by a number of people. A formal process like this generally helps an individual with disabilities to develop a vision and plan for his/her future at any time in a person’s life, and can be especially helpful when approaching a life transition. Person-Centered Planning relies on the commitment of a team of individuals who care about an individual. Team members may vary but often include parents/guardians, other family members, friends, professionals, and anyone else who has a personal relationship with the individual. These individuals often meet several times to identify opportunities and strategies for the person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve their goals. These committed participants have the

responsibility to ensure that the strategies decided in the planning meetings are actually implemented.

Family Support Centers can be a great venue for families to learn more about Person-Centered Planning. If an individual and/or family decide they would be interested in exploring and/or doing a Person-Centered Planning process, they may need assistance from a Family Support Navigator or the Area Office. This might include locating an experienced and neutral facilitator who is able to lead the group through the process. If a family receives a flexible funding allocation, they may choose to use a portion of it to cover the cost of hiring a professional Person Centered Planning facilitator.



NICK

In preparation for his IEP meeting, Nick wrote: “I want to have a paid job working with horses, to continue working out at the Y and making new friends and to have opportunities to play music and perform in Community Theatre.” Nick is now living his dream!

From his Inclusion Award Nomination.

ROBERT



Robert building sets for an upcoming theatre production at Bridgewater State University.

Robert is living a full life with the help of his supportive family and the Building Futures Project at The Nemasket Group. Robert attended the Bridgewater State University for three years as part of Massachusetts Inclusive Concurrent Enrollment Initiative. He audited a variety of undergraduate classes in the performing arts as well as participated in several on-campus internships involving theatre production. He became actively involved in campus activities like any typical college student. Robert also joined a local theatre group and appeared in a number of its productions, including *Fiddler on the Roof* and *Hairspray*. In 2016, he worked as an extra in a major studio film “Bleed For This” after responding to an advertisement in a local newspaper. It is wonderful to see how Robert has become the lead actor in his own life!

For more information on the Building Futures Project, go to www.Nemasketgroup.org/building-futures/

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- **Person Centered Planning and LifeCourse Charting Resources: Charting the LifeCourse Framework and Tools** was developed by families to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. If you are interested in learning more about this framework, you can find it at <https://www.lifecoursetools.com/>
 - If a family is interested in a more formal **Person Centered Planning (PCP)** process, there is a Transition Information Fact Sheet #2 which describes the PCP process. It can be found at <http://www.mass.gov/eohhs/docs/dmr/dds-transition-sheets-2015.pdf>

Massachusetts Department of Developmental Services

Section: IV – Culturally and Linguistically Responsive Family Support

A. Overview

The Department of Developmental Services (DDS) is committed to ensuring that family supports are provided in ways that respect and honor the cultural, religious, linguistic and individual differences and values of families across the state. It has been well documented that families from culturally and linguistically diverse communities have frequently been either unserved or underserved in social services or healthcare systems. This is related to factors such as language barriers, trust issues, fear of governmental agencies, and attitudes toward people with disabilities in some cultures as well as a general lack of knowledge in how to access services.

In order to respond to the needs of culturally and linguistically diverse individuals and families, the Department has established priorities for itself and its service providers in increasing staff diversity, cultural knowledge and bilingual capacity. Recognizing these priorities, the Department has started several initiatives over the years.

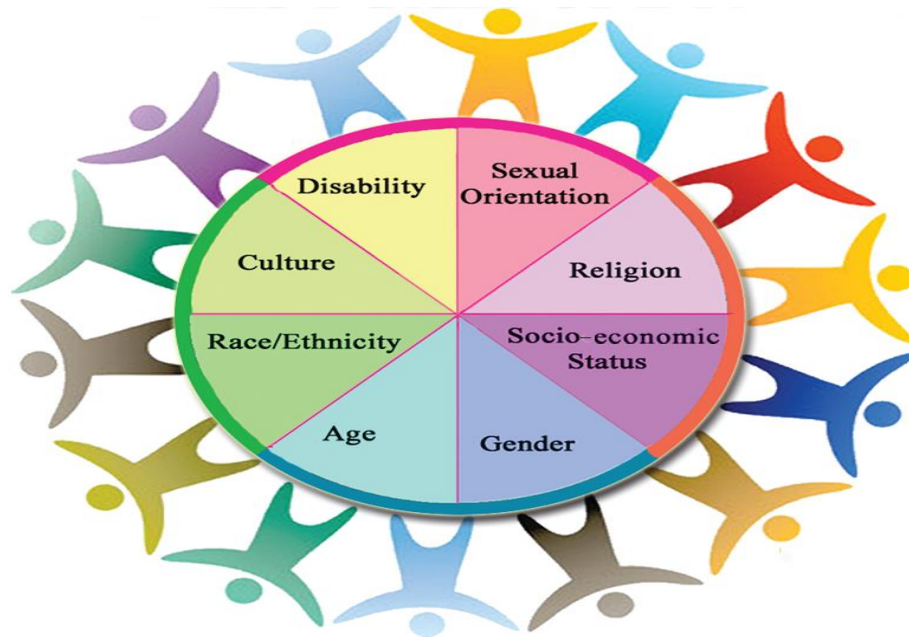
1. When the Department procured its family support services in FY'10, it included funding for ten Cultural/Linguistic-Specific Family Support Centers in order to continue specific existing cultural outreach initiatives across the state.

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 are expected to provide broad outreach and are frequently called upon by other organizations to help provide interpretation and translation assistance to families. These Centers primarily provide services to families who speak Spanish, Chinese, Vietnamese, Khmer, Russian, Haitian Creole, Portuguese, and Cape Verdean Creole.

2. In addition, the Department requires all Family Support Centers and providers to develop resources and capacity to do outreach and be responsive to the diverse cultural and linguistic communities in the geographic area(s) in which they are providing services.
3. DDS has organized active Statewide, Regional and Central Office Diversity Councils that offer a variety of opportunities for education, training and cultural experiences to promote increased understanding of different cultural and linguistic groups, and support the delivery of more culturally responsive services.
4. The Department focused one of its early Statewide Family Support Conferences on June 3, 2015, on “Family Diversity in Our Contemporary Society”, featuring its Keynote Speaker, Tawara D. Goode, Director, National Center for Cultural Competence, Georgetown University Medical Center.

The conference had three stated goals:

- To respect and celebrate the broad family diversity found in today’s society;
- To provide specific strategies and tools to assist people in effectively supporting diverse family caregivers; and,
- To create a deeper understanding of other complicating factors that affect family access to services, such as poverty, language and culture.



5. DDS continues to offer training opportunities for family support and DDS staff focused on increased understanding of families from diverse communities and to learn more about resources and strategies to provide culturally respectful and responsive services. The Department fosters learning from staff at the Cultural/Linguistic-Specific Family Support Center and provides opportunities to hear directly from families from diverse communities about their experiences and perspectives in raising a child with a disability, and from providers about the approaches they have developed and used to offer culturally responsive services. Through Regional meetings DDS staff continues to work collaboratively with providers to share positive practices and support them as they further develop their capacity to provide services to individuals and families from diverse communities.

6. The Department of Developmental Services has developed a Language Access Plan (LAP) which ensures individuals and their families are receiving meaningful access to services, programs and activities although they may be limited in their English language proficiency. This applies to both the Department and its service providers. Consistent with the guidance of ANF Administrative Bulletin #16, a Limited English Proficient (LEP) person is someone who is not able to speak, read, write or understand the English language at a level that allows him/her to interact effectively with Agency staff. An individual maintains the right to self-identify as a Limited English Proficient (LEP) person. This Language Access Plan (LAP) outlines the Agency's commitment to providing universal access for all individuals, whether they are served by the Agency or seeking to participate in services, programs, and activities including individuals who are deaf, late deafened, and hard of hearing. The Language Access Plan is now on the DDS website, under Policies. Direct link www.mass.gov/find-dds-regulations-policies-public-hearings

Additionally, the Department has the following expectations for itself and its family support programs:

- To hire staff who represent the various diverse cultures and languages of the people living in the catchment areas of DDS and its family support programs.
- To create an effective local outreach plan to connect with families from underserved cultural groups in each catchment area.
- To offer trainings for family support staff to learn more about different cultures in the community, how their culture views disability and ways to engage individuals and families in services.
- To develop a “front door” plan that is both accessible and welcoming for people who come from a different culture and/or speak another language (i.e. an effective telecommunication system, a comfortable and inviting reception area, etc.)
- To secure skilled cultural interpreters and translators in a timely fashion when needed.
- To provide translation of written information and forms used in communication with individuals and families in their preferred language.
- To develop local partnerships with grassroots multicultural organizations in communities.
- To support the individuals we serve to participate in multicultural fairs and events in their community and if interested, to become actively involved in such organizations.
- To involve diverse individuals and families on local Advisory Boards and Family Support Councils for their input on family support planning, implementation and quality assurance.

The journey to provide culturally responsive family supports is a never ending one which the Department recognizes and will continue its commitment to these important goals and efforts.



B. Translation and Interpretation Services

1. Translation: The Department makes available translated informational materials in multiple languages, including vital documents that individuals and families need to approve and sign. Effective 10/1/16, DDS must utilize only qualified providers (i.e. vendors who have been reviewed under the state contract PRF 63) for Foreign Language Interpretation and Translation Services. This list of qualified providers developed by OSD for state agency use is listed in Comm-BUYS (and these agencies can be contracted by family support providers separately if they choose).

For DDS staff, the following four agencies have been qualified and selected to provide in-person interpretation and document translation for DDS. It is up to provider agencies to provide their own translation and interpretation services. They may choose to contract with one of these qualified entities below, or may use other community services and resources.

Bay State Interpreters Darrin Brooks dbrooks@baystateinterpreters.com 978-632-1662 ext. 2020 55 Lake Street #300 Gardner MA 01440	Cross Cultural Communications Systems Linda Demmons Linda_contracts@embracingculture.com 781-729-3736 PO Box 2308 Woburn MA 01888
Language Bridge <i>(Note: Only available in Central/Western MA)</i> Lyudmila Dubinchik mila.dubinchik@comcast.net 413-478-2598 PO Box 60503 Longmeadow MA 01116	TransPerfect Global Michael Macrina mmacrina@transperfect.com 202- 347-2300 700 6th NW Washington DC 20001



“If you talk to a man in a language he understands, that goes to his head. If you talk to him in his own language, that goes to his heart.”

Nelson Mandela

2. Interpreting Services

The following agency has been qualified to provide telephonic interpretation for DDS:

- **Telelanguage**

This is a service that provides access for non-English-speaking families to contact DDS by phone and for DDS staff to communicate with individuals and families about appointments, etc. and will complement in-person interpretation.

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

Requests for ASL interpreters are made either directly by Deaf, Deaf-Blind, late deafened, hard of hearing and hearing individuals and/or agencies, organizations, schools, employers, businesses, doctors, hospitals, police departments, and courts.

MCDHH Interpreter Service

600 Washington Street,
Boston, MA 02111

617-740-1600 (Voice)

617-740-1700 (TTY)

800-882-1155 (Toll Free TTY)

617-740-1880 (Fax) with a interpreter/CART Request Form

Emergency: Legal emergencies are received 24 hours 7 days/week at 800-249-9949 TTY/VOICE.

Hours: 8:45 AM - 5:00 PM, Monday - Friday

[MCDHH Request for An Interpreter](#)

3. Other Resources:

The New England Index also maintains a list of resources for providing interpretation and translation services at www.disabilityinfo.org.



“ASL (American Sign Language) Spoken Here” icon

C. Helpful Definitions

The Department's Language Access Plan provides a list of helpful definitions that assist family support staff and DDS staff in obtaining and working effectively with skilled interpreters and translators to assist families for whom English is not their primary language;

- **Primary Language** - The language in which the individual most effectively communicates.
- **Effective Communication** - Communication sufficient to provide the Limited English Proficient (LEP) Individual or persons with substantially the same level of services received by individuals who are not LEP.
- **Meaningful Access** - Language assistance that results in accurate, timely, and effective communication for the LEP individual.
- **Language Assistance Services** - Oral and written language services needed to assist LEP individuals to communicate effectively with staff, and to provide LEP Individuals or persons with meaningful access to, and an equal opportunity to participate fully in, the Agency's services, activities, or other programs.
- **Interpretation** - The immediate oral communication of meaning from one language (the source language) to another (the target language).
- **Translation** - The act of conveying meaning from written text in one language (source language) to written text in another language (target language).
- **Bilingual Staff** - A staff member who demonstrates an ability to speak, and/or read/write at a native or near-native fluency in at least one other language in addition to English.
- **Vital Document** - Paper or electronic written material that contains information that is critical for accessing services, programs or activities, or is required by law.
- **Direct "In-Language" Communication** – Monolingual communication in a language other than English between a multilingual staff and an LEP person (e.g., Korean to Korean).

D. Helpful Resource

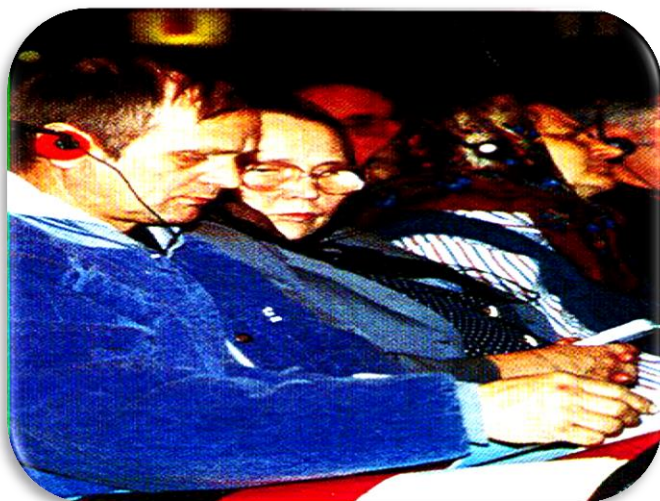
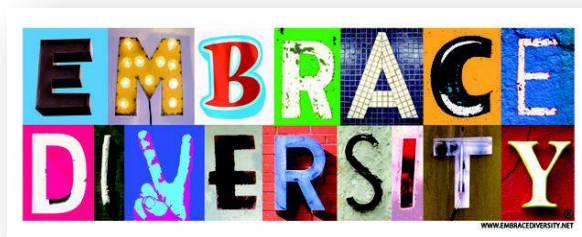
The National Center for Cultural Competence (NCCC) provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education and advocacy.

The NCCC is a component of the Georgetown University Center for Child and Human Development (GUCCHD) and is housed within the Department of Pediatrics of the Georgetown University Medical Center.

The NCCC provides training, technical assistance, and consultation, contributes to knowledge through publications and research, creates tools and resources to support health and mental health care providers and systems, supports leaders to promote and sustain cultural and linguistic competency, and collaborates with an extensive network of private and public entities to advance the implementation of these concepts.

Contact Information:

National Center for Cultural Competence
Georgetown University Center for Child and Human Development
Georgetown University
Box 571485
Washington, DC 20057
Phone: 202-687-5387 or 800-788-2066
Fax: 202-687-8899
E-mail: cultural@georgetown.edu



**Simultaneous Interpreting for
Russian-Speaking Families
attending a Diversity Conference.**

Massachusetts Department of Developmental Services

Section: V – Determining Eligibility For DDS Services

In order to receive services and supports from the Department of Developmental Services, including Family Supports, children and adults must be determined to be eligible in accordance with Department regulations. [See 115 CMR 2.01 and 6.0]. Eligibility for DDS services will be determined through a Regional Eligibility Team process. Descriptions of the eligibility criteria and eligibility regulations are available online at www.mass.gov/dds.

Where to Get an Application:

- Go to mass.gov/dds-eligibility-services
- Applications can also be found at Family Support Centers and DDS Area Offices. Eligibility Forms are available in several languages. Other languages are made available upon request.

Family Support and Autism Support Centers are able to assist families in submitting an application for eligibility and provide assistance and support throughout the intake process as requested by families. This includes helping families understand how to complete the necessary steps to apply for DDS eligibility (e.g., whom to call, paperwork). Families are able to access some of the general services of the Family Support and Autism Support Centers prior to their child or adult family member being found eligible for DDS services, such as Information and Referral and trainings.

ELIGIBILITY CRITERIA

There are different eligibility criteria and applications for children and adults.

For Children Services:

Individuals can be determined eligible for children services through the Department of Developmental Services (DDS) if they meet the identified eligibility criteria according to their age when they apply:

- **0 up to 5 years:** individuals have a substantial developmental delay, as determined by a qualified, licensed clinician.
- **5 up to 22 years** individuals have an intellectual or closely related developmental disability, as determined by a qualified, licensed clinician and verified by DDS, and result in substantial functional limitations.

For Adult Services:

Individuals can be determined eligible for adult services through the Department of Developmental Services (DDS) if they have significant limitations in adaptive functioning and one or more of the following diagnoses:

- Intellectual Disability
- Autism Spectrum Disorder
- Prader-Willi Syndrome
- Smith-Magenis Syndrome

In order to receive services at age 22 or later, adult eligibility must be completed, even if the individual has been determined eligible for children's services. It is best to begin the adult eligibility

process around age 17-17.5 in order to provide maximum planning time for adult services. When an individual has their 22nd birthday, DDS children's services end and, if eligible, adult services begin.

Steps in the Eligibility Process:

1. Once the application and all the required paperwork are submitted, the family is contacted by an Intake and Eligibility Specialist to set up an Intake Interview. This involves a face-to-face interview, including an assessment of the individual's skills. DDS makes interpreters and translated materials available in order to communicate effectively with families. Family privacy and confidentiality are respected at all times.
2. After the Intake Interview, all the materials and information are reviewed by the Regional Eligibility Psychologist based on the identified eligibility criteria. The applicant or guardian is notified in writing of the Eligibility Determination indicating whether the individual is eligible or not eligible. If eligible, the individual and family are given information about their local Area Office and contact person. If determined ineligible, the individual and family receives information about the DDS appeal process.
3. Once found eligible for DDS services, individuals and families are also sent a "Welcome to DDS Flier" with information about the Family Support Centers and Autism Support Centers in their area. If not already connected to a Center, the flier gives families information on how to make that contact. This notice is available in multiple languages in order to assist families for whom English is not their primary language.
4. Family and Autism Support Center Navigators can help families in problem-solving current issues they are facing by exploring other generic resources and entitlements. The DDS Area Office Service Coordinator is also an important resource for connecting the individual and family with any other family supports or services based on their needs. Some family supports may be dependent on the availability of resources and prioritization.

Statewide Intake & Eligibility Contacts

Regional Eligibility Coordinators

More information about the eligibility process as well as the application forms can be found on the DDS website, www.mass.gov/dds

DDS Central/West Region

Regional Eligibility Coordinator

140 High Street, 1st Floor
Springfield, MA 01105

Intake Line: (413) 205-0940

Fax Number: (413) 205-1603

DDS Metro Region

Regional Eligibility Coordinator

465 Waverley Oaks Road, Suite 120
Waltham, MA 02452

Intake Line: (781) 314-7513

Fax Number: (781) 314-7539

DDS Northeast Region

Regional Eligibility Coordinator

Hogan Regional Center

PO Box A

Hathorne, MA 01937

Intake Line: (978) 774-5000 x850

Fax Number: (978) 739-0420

DDS Southeast Region

Regional Eligibility Coordinator

151 Campanelli Drive, Suite B

Middleboro, MA 02346

Intake Line (508) 866-5000

Fax Number (617) 727-7822

WELCOME LETTER

Once found eligible for DDS services, individuals and families are also sent a “Welcome To DDS Flier” with information about the Family Support Centers and Autism Support Centers in their area. If not already connected to a Center, the flier gives families information on how to make that contact. This notice is available in multiple languages in order to assist families for whom English is not their primary language.

WELCOME TO DDS

SUPPORTS YOU CAN ACCESS NOW!

Family Support Centers across the state funded by the Department of Developmental Services (DDS) provide information, assistance, and a variety of supportive services to families with children and adults with intellectual and developmental disabilities who are living at home.

How Can A Family Support Center Help You?

- By providing information and assistance in obtaining a wide array of services including but not limited to:
 - Social and recreational opportunities
 - Support groups for parents, siblings and family members
 - Resources in your community
 - Public benefits for which you may qualify
- By presenting the option to attend trainings or receive information on topics such as:
 - Guardianship/Trusts
 - Planning for the Future
 - Social Skills
 - Human Relationships
 - Specific disabilities and/or conditions
- By offering opportunities to meet other families through networking and organized social and community activities

As a family eligible for services from DDS, we encourage you to contact one of the Family Support Centers and the local Area Office near you. In the following pages you will find Center names, addresses and website addresses where you can learn more about the supports and activities provided by that Center. A directory with the contact information for these Centers and the local Area Office is also available on the DDS web-site at www.mass.gov/dds.

10/12

Massachusetts Department of Developmental Services

Section: VI – Family Support Program Services

A. Family Support Centers

Service Description:

Family Support Centers are expected to establish a local presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults who are eligible for DDS services. There is at least one Family Support Center that will provide services to families in each DDS Area across the state. This will ensure that families have equal access to family support center activities and services. Family Support Centers conduct broad outreach and provide services to families from diverse cultural, ethnic and linguistic communities in the geographic area they are serving. This involves creating partnerships with community organizations and other resources in order to provide culturally responsive services.

These Centers encourage active family involvement and consultation to identify interests and needs in developing Center activities and service options. Family Support Center staff provide an array of services and supports to families that include: information and referral, access to technology, support groups, family trainings, parent networking and mentoring, facilitation of social/recreational events, among other activities. Information and Referral services can include individualized consultation and support over a course of a few meetings for families who need and can benefit from more “hands- on assistance.”

Centers also provide Service Navigation for families who need or will benefit from this service. This service includes comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving and help them navigate the service system.

Family Support Centers are expected to be highly integrated within their local communities. This includes developing strong local affiliations and partnerships with other state and grassroots community agencies in order to expand opportunities and services for individuals and families. Family Support Center staff become experts in generic resources and services in their respective areas and work to maximize natural supports.

Service Elements:

Each Family Support Center will offer the following services in its defined geographical service area:

1. Information & Referral:

- Provide timely and quality Information & Referral Services to families of children and adults who contact the Family Support Center. This involves assisting families in identifying resources and service options available in their local communities, as well as learning about other financial and/or state services for which families may be eligible (MassHealth, etc.), and provide guidance on how to navigate the service system. This occurs through phone contacts and/or individual consultation with families at the Center or in other locations in the community. Some families may benefit from more in-depth support over the course of a few meetings to obtain information and get advice on accessing services, or may need some time-limited, hands-on support.
- Expand use of technology to provide a variety of ways to share information with families. This should include the development of an agency web-site, on-line newsletters and training calendars, and other ways to connect families through technology.

- Create and maintain a “library” of resources, such as helpful websites, fact sheets, community resources, information technology resource options, books, videos, etc. Centers also need to develop a variety of ways to communicate and share information with families to be responsive to the multiple needs of families, including those who do not have access to or are not comfortable using computers, who have limited literacy, and/or for whom English is not their first language.

2. Family Trainings:

- Sponsor educational events and trainings on relevant topics of interest to families of both children and adults which are open to all families for participation. Each Family Support Center is expected to offer a minimum of six trainings per year that will address the common topical areas that are relevant to families across the lifespan.
 - A. Topics include: 1) accessing public benefits and entitlements; 2) understanding basic educational rights and the Individual Education Plan (IEP); 3) transition from high school; 4) guardianship and other options; 5) planning for the future; 6) sibling workshops; and 7) other relevant topics. Families are encouraged to identify topics of interest that may result in offering trainings on specialized areas of focus.
 - B. Providers are able to arrange or co-sponsor trainings with other organizations and/or directly provide training on topics relevant to families. In order to ensure access for families, the Center varies the venues throughout the community, inviting guest speakers and collaborating with community agencies and other providers. Centers also support families to participate by providing assistance with transportation, child care, etc.
- Provide information about other interesting presentations available in the community sponsored by other organizations, for example, the Federation for Children with Special Needs on educational rights, the ARC on financial planning, local Parent Advisory Councils.
- Collaborate with other providers and Centers in the region to plan and coordinate training and other educational opportunities to maximize resources and opportunities for families.

3. Parent Networking:

- Promote parent networking and mentoring, such as parent support groups, parent connections (1:1 matching), and sibling support opportunities, as well as parental involvement in organizing or leading activities, etc.

4. Community Connections & Resources:

- Foster community affiliations and connections to explore and maximize the use of natural and generic resources and other potential sources of funding, among other activities, such as those set forth below:
- Offer social/recreational opportunities in partnership with other providers and community resources (e.g. YMCA, recreational centers, neighborhood community centers, Boys’ and Girls’ Clubs, etc.).
- Pursue alternative funding/grants to expand opportunities for individuals and families.
- Recruit volunteers and student interns to support the above Center activities from local colleges, high schools and other community resources including senior citizens.

5. Service Navigation:

This service is available to families of both children and adults with an expressed need for and interest in intensive time-limited or ongoing assistance in a specific area or areas. Service Navigation is the provision of comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving, and help

them navigate the service system. The level of involvement with each family varies based on the needs of the individual and family. It is expected that a family support plan will be developed with each family receiving either short-term or extended Service Navigation in order to identify and address their priority needs.

The availability of both time-limited and extended Service Navigation is designed to be responsive to the changing and dynamic needs of families and to maximize the resources of the Center to meet the specific needs of families. It is expected that Family Support Center staff work in close collaboration with the Area Office to review use of this service, capacity, need, and referrals in order to optimize the resources available. Each Family Support Center provides two types of Service Navigation:

- **Short-Term Service Navigation:** is designed for families who will benefit from more individualized assistance for a period of time to obtain information, to receive assistance in accessing other services, or to receive guidance in addressing some specific problems. For example, this service may be particularly helpful to families going through a key transition, such as movement from middle school to high school. Even though this service is short-term, if the families' circumstances change and other needs arise, they could access this service again. Families can access this service directly with the Center, the Family Support Center may identify families who will benefit from this service, and Area Offices will refer families for this service.
- **Extended Service Navigation:** It is expected that each Family Support Center will also have a designated amount of capacity to provide extended Service Navigation to identified individuals and families who require ongoing support and coordination of services. Individuals and families will ultimately need to be referred by the Area Office for this service, but the request for this service can be initiated by the family, Family Support Center staff, or the Area Office. This referral process and ongoing communication and collaboration between the Area Office and Center are important to help manage capacity and facilitate access to services for families and individuals. This service is also designed to assist families to help plan and organize in-home supports they need to support their family member at home. It is expected that a Family Support Plan will be developed with each family.

6. Administration Of Flexible Funding:

Family Support Centers need to be prepared to administer flexible funding allocations. This entails issuing stipend checks or reimbursement checks to families, or paying vendors for goods or services provided to families. Per Chapter 257 of the Acts of 2008, the Department, in concert with the Executive Office of Health and Human Services (EOHHS) has established a transaction fee for the administration of flexible funding which includes the activities associated with issuance of stipends, reimbursement to families, and payment to third party vendors. (See Section VII, Individual Flexible Funding Allocations for details)

Providers who administer flexible funding are required to perform the following activities:

- Discuss with families the potential use of these funds to ensure that usage is in compliance with the Family Support Guidelines. If there are questionable activities etc., the Family Support Center needs to consult the Area Office overseeing the Family Support Center contract. The Regional Family Support Director is also a resource to help address questions or issues that arise.
- Provide information to families who are receiving stipends about the importance of complying with all rules and requirements about the hiring and payment of potential employees. Family Support Centers should not offer tax advice to families.
- Complete the Flexible Funding Expenditure Plan with families to record uses of funding.
- Have a system in place to track these funds by individual family and maintain a record of activity, which is communicated with the Area Office on a regular basis.

Programmatic Requirements and Expectations:

- Program staff will meet all DDS mandatory training requirements, as contained in DDS regulations.
- The Family Support Center must have a main office site that is centrally located and accessible to the majority of the families it serves. It must also make local arrangements with community resources (i.e. libraries, schools, etc.) for space to hold family meetings and trainings as needed to create equal access for families across the geographic area.
- Family Support Center services must be available on a schedule that is flexible and responsive to the needs and lifestyle demands of families, which may include some evening and week-end hours.
- Family Support Centers must create access and be responsive to cultural and linguistic communities in the geographic area.
- Staff need to be mobile and able to meet families in their homes and local communities.

Data and/or Reporting Requirements:

Family Support Centers are required to submit the *Family Support Centers Semi-Annual Data Report* twice a year. (See Section XII, Family Support Centers)

Family Support Centers participate in the *Family Support Center Quality Review* process with the Area Office each year. (See Section XIII, D)

Family Stabilization Services Rates:

Per Chapter 257 of the Acts of 2008, the Executive Office of Health and Human Services (EOHHS) has responsibility for establishing rates of payment for social service programs purchased by the Department of Developmental Services. The following program comes under Chapter 257 and regulated rates of payment have been established by the Executive Office (EOHHS):

Family Support Centers/Autism Support Centers: Monthly Accommodation Rate based on number of Service Navigator full time equivalents (FTE)

Rates are periodically reviewed and are subject to change. Any changes to the Family Stabilization regulation, **101 CMR 414.00**, are posted by the Executive Office of Health and Human Services and can be found via the following link: <http://www.mass.gov/eohhs/gov/laws-regs/hhs/purchase-of-service-rates-for-social-services.html>

An Array Of Services And Activities Provided By DDS Family Support Centers

Information & Referral



**Transition Fair at Northampton High School;
Partnership between Family Empowerment
Center and Franklin/Hampshire Area Office**

Training Opportunities



**Family Empowerment Center hosts ARICA
training provided by Amy Weinstock from the
Autism Insurance Resource Center.**

Social and Recreational Activities



**A Winning Track Club from the
Communitas Family Resource Center**

Service Navigation



**A Family Navigator helps a family with
completing an application at the MCS
Family Support Center in Holyoke**

Support Groups



WE ARE FAMILY!

Brothers and sister supporting each other. Two of the siblings participate in Sibling Support Group offered by the Communitas Family Resource Center.



Teen Support Group at Brockton ARC Family Support Center

B. Cultural/Linguistic-Specific Family Support Centers

Service Description:

Cultural/Linguistic-Specific Family Support Centers are designed to respond to the unique needs of specific cultural and linguistic family groups in specified areas or regions of the state. Families who receive these services are typically designated groups of families for whom English is not their primary language. As a result, they face linguistic barriers in accessing services and require more individualized and specialized assistance to learn about and access the service system. Due to language barriers, many of these families face extraordinary challenges accessing services including housing, employment, health care, and education. These families require skilled staff with strong experience and expertise in accessing entitlements and other generic resources. In order to deliver culturally competent supports, these Centers assist families in navigating the service system with staff who are bilingual in the primary languages spoken by the families and have a good understanding of the cultural values, beliefs and traditions of the families being served.

These Centers need to be rooted in communities and act as a hub for offering a range of family support services and activities to families of both children and adults who are eligible for DDS services. Cultural/Linguistic-Specific Family Support Centers encourage active family involvement and consultation to identify interests and needs in developing activities and service options. Center staff provide services and supports to families including information and referral, support groups, family trainings, parent networking and mentoring, and facilitate social/recreational events, based on the priority needs of families.

These Centers also provide Service Navigation for families who need or will benefit from this service. This service includes comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving and help them navigate the service system.

Centers are highly integrated within their local communities. It is expected that they develop strong local affiliations and partnerships with other state agencies and community organizations in order to expand opportunities and services for individuals and families. Center staff need to become experts in generic resources and services in their respective areas.

Service Elements:

These Centers offer the following service elements in its defined geographical service area to the designated population of families:

1. Information & Referral:

- A. Provide timely and quality Information & Referral services to families of children and adults who contact the Center. This involves assisting families in identifying resources and service options available in their local communities, as well as learning about other financial and/or state services for which families may be eligible (MassHealth, etc.), and provide guidance on how to navigate the service system. This occurs through phone contacts and/or individual meetings with families at the Center or in other locations in the community. It is expected that this will be a hands-on and more time intensive service for families who do not speak English.
- B. Create and maintain resources that are helpful to families including information that is translated and/or available in the primary language of families. This includes helpful

websites, fact sheets, community resources, information technology resource options, books, videos, etc.

2. Family Trainings and Parent Networking:

- A. Sponsor educational events and trainings on relevant topics of interest to families of both children and adults which are open to all families for participation.
- B. Provide information about other interesting presentations available in the community sponsored by other organizations, for example, the Federation for Children with Special Needs on educational rights, the ARC on financial planning, etc.
- C. Promote parent networking and mentoring, such as parent support groups, parent connections (1:1 matching), family events, and sibling support opportunities, as well as parental involvement in organizing or leading activities, etc.

3. Community Connections & Resources:

- A. Facilitate social/recreational opportunities in partnership with other providers and community resources (YMCA, recreational centers, neighborhood community centers, Boys' and Girls' Clubs, etc.).
- B. Foster community affiliations and connections to explore resources and other potential sources of funding, among other activities.
- C. Pursue alternative funding/grants to expand opportunities for individuals and families.
- D. Recruit volunteers and student interns to support the Center activities from local colleges, high schools and other community resources including senior citizens.

4. Service Navigation:

This service is available to families of both children and adults with an expressed need and interest for intensive time-limited or ongoing assistance in a specific area or areas. Service Navigation is the provision of comprehensive and individualized information, guidance, and support to families to address their needs, connect them to potential resources, assist with problem-solving, and help them navigate the service system. The level of involvement with each family varies based on the needs of the individual and family.

The availability of both time-limited and extended Service Navigation is designed to be responsive to the changing and dynamic needs of families and to maximize the resources of the Center to meet the specific needs of families. It is expected that Center staff work in close collaboration with the Area Office to review use of this service, capacity, need, and referrals in order to optimize the resources available. Each Cultural/Linguistic-Specific Family Support Center provides two types of Service Navigation.

- **Short-term Service Navigation:** is designed for families who need or will benefit from more individualized assistance for a period of time to obtain information, receive assistance in accessing other services, or to receive guidance in addressing some specific problems. For example this service may be particularly helpful to families going through a key transition, such as movement from middle school to high school. Even though this service is short-term, if the families' circumstances change and other needs arise, they could access this service again, based on available capacity. Families can access this service directly with the Center, the Family Support

Center may identify families who will benefit from this service, and Area Offices will refer families for this service. It is expected that a family support plan will be developed with each family.

- **Extended Service Navigation:** It is expected that each Family Support Center has a designated amount of capacity to provide extended Service Navigation to some identified individuals and families who require ongoing support and coordination of services. Individuals and families ultimately need to be referred by the Area Office for this service, but the request for this service can be initiated by the family, Family Support Center staff, or the Area Office. This referral process and ongoing communication and collaboration between the Area Office and Center are important to help manage capacity and facilitate access to services for families and individuals. This service is also designed to assist families to help plan and organize in-home supports they need to support their family member at home. This service may be provided to some families of adults who are enrolled in the Department's Adult Support Waiver Program, and for this group there will be specific requirements in terms of frequency of contact and reporting that will apply. It is expected that a family support plan will be developed with each family.

5. Administration of Flexible Funding:

Flexible funding refers to the individual resource allocation attributed to a specific family. Once the Department has determined who may receive an individual resource allocation, the Department and the family will need to determine how that resource will be delivered to the family. All individual resource allocation expenditures must be for permissible supports, services, or goods as defined in the Department's Family Support Program Manual. **(Section VII)**

Centers need to be prepared to administer flexible funding allocations. This entails issuing stipend checks or reimbursement checks to families. The Department in concert with the Executive Office of Health and Human Services (EOHHS) has established a single administrative rate for the administration of flexible funding which will include the activities associated with issuance of stipends, reimbursement to families, or direct payment to 3rd party vendor.

Programmatic Requirements and Expectations:

- Program staff will meet all DDS mandatory training requirements, as contained in DDS regulations.
- The Center must have a main office site that is centrally located and accessible to the majority of the families they serve. It must also make local arrangements with community resources (i.e. libraries, schools, community agencies, etc.) for space to hold family meetings and trainings as needed to create equal access for families across the geographic area.
- Family Support Center services must be available on a schedule that is flexible and responsive to the needs and lifestyle demands of families, which may include some evening and week-end hours.
- Program staff need to be mobile and able to meet families in their homes and local communities.

Data and/or Reporting Requirements:

Cultural/Linguistic-Specific Family Support Centers are required to submit the Family Support Center Semi-Annual Data Report twice a year. **(See Section XII, Family Support Centers)**

Cultural/Linguistic-Specific Family Support Centers participate in the *Family Support Center Quality Review* process with the Area Office each year. **(See Section XIII, D)**

Family Stabilization Service Rates:

Per Chapter 257 of the Acts of 2008, the Executive Office of Health and Human Services (EOHHS) has responsibility for establishing rates of payment for social service programs purchased by the Department of Developmental Services. The following program comes under Chapter 257 and regulated rates of payment have been established by the Executive Office (EOHHS):

Family Support Centers/Autism Support Centers: Monthly Accommodation Rate based on number of Service Navigator full time equivalents (FTE)

Rates are periodically reviewed and are subject to change. Any changes to the Family Stabilization regulation, **101 CMR 414.00**, are posted by the Executive Office of Health and Human Services and can be found via the following link: <http://www.mass.gov/eohhs/gov/laws-regs/hhs/purchase-of-service-rates-for-social-services.html>

CULTURAL/LINGUISTIC SPECIFIC Family Support Centers



Chinese and Vietnamese Families Celebrate the Lunar New Year at the Project Able Family Support Center's annual New Year's event.



Families from East Africa Center holding community meeting at SC@N360 Family Support Center.

C. Autism Support Centers

Service Description:

The goal of the Autism Support Centers is to provide an array of information and referral services, resources and supports to children and adults with autism spectrum disorders. The array of services and supports to families includes information and referral, family clinics, support groups, access to the latest information on autism, family trainings, parent networking and mentoring, and social/recreational events, among other activities. The Autism Support Center needs to establish a local presence and demonstrate an expertise in autism spectrum disorders. There are seven Autism Support Centers across the state to insure that families have access to center activities and services. It is expected that Autism Support Centers conduct broad outreach and provide services to families from diverse cultural, ethnic and linguistic communities in the geographic area they are serving. This involves creating partnerships with community organizations and other resources in order to provide culturally responsive services. The Autism Support Centers are expected to work collaboratively with the DDS Area Offices.

Since 2015, the scope of Autism Support Center's work has expanded to include services to adults with Autism who do not have an intellectual disability and their families.

Autism Support Centers encourage active family involvement and consultation to identify interests and needs in developing Center activities and service options. Autism Support Centers should be highly integrated within their local communities. The Centers need to develop strong local affiliations and partnerships with other state entities and grassroots community agencies in order to expand opportunities and services for individuals and families. Autism Support Centers need to become experts in generic resources and services in their respective areas.

Service Elements:

Each Autism Support Center offers the following service elements in its defined geographical service area:

1. Information & Referral:

- A. The Autism Support Centers provide coordination for families related to their family member's autism spectrum diagnosis. This includes information and referral to other state systems for support including supplemental help from other health and human service agencies (Early Intervention, Department of Mental Health, and MassHealth), connections to local resources such as after school, vacation, sports and socialization programs, and information on local specialists and related healthcare providers, such as dentists, who have experience with children/young adults on the spectrum.
- B. Create and maintain a "library" of resources, such as helpful websites, fact sheets, community resources, information technology resource options, books, videos, etc. Create and maintain an electronic monthly newsletter for families—highlighting events sponsored by the Center as well as events of interest in the community. Provide families links to timely and relevant autism topics on the agency's website.
- C. Provide appropriate informational resources to families of transitional age youth including information on next steps, exploration about guardianship issues, vocational supports, and information about the adult service system.

- D. Provide information and consultation about Autism Spectrum Disorders to other DDS providers including adult residential and day service providers to increase knowledge and expertise across the region.
- E. Work collaboratively with the DDS Area Offices to respond to the needs of families.

2. Family Trainings:

Sponsor educational events and trainings on relevant topics of interest that are open to all families for participation. It is expected that each Autism Support Center will offer a minimum of 4 to 6 trainings per year that will cover a consistent menu of topical areas across the autism spectrum. Providers may arrange or co-sponsor trainings with other organizations and/or directly provide training on topics relevant to families.

In order to insure access for families, the Center should vary the venue throughout the community, inviting guest speakers and collaborating with community agencies and other providers.

Provide information about other relevant presentations available in the community sponsored by other organizations, for example, with the Federation for Children with Special Needs on educational rights, in-home ABA services, the ARC on financial planning, etc.

3. Parent Networking:

The Center should help to promote parent networking and mentoring. The Center should hold parent support groups, create opportunities for parent connections (1:1 matching) and provide opportunities for sibling support through a variety of workshops and outings. The Center should also encourage and support parents to lead activities and groups.

4. Community Connections & Resources:

- A. Facilitate social/recreational opportunities in partnership with other providers and community resources on a regular basis (YMCA, recreational centers, Boys' and Girls' Clubs, etc.).
- B. Foster community affiliations and connections to explore resources and other potential sources of funding, among other activities.
- C. Pursue alternative funding/grants to expand opportunities for individuals and families.
- D. Recruit volunteers and student interns to support Center activities from local colleges, high schools and other community resources.

5. Social Skills And Vacation/Family Programs:

- A. The Autism Support Center will coordinate social skills programs for children and adults across various age spans and abilities.
- B. The Autism Support Center will hold sensory programs, such as a gym and/or swim classes for a variety of age spans and abilities at various locations across the service area.
- C. The Autism Support Center will hold vacation/family programs for a variety of age spans and abilities.

6. Services For Adults With Autism (W/O An Intellectual Disability) And Their Families:

The Autism Support Centers have staff to support newly-eligible adults with Autism without an Intellectual Disability and their families. This includes:

- A. Engaging the expansion population of individuals with autism w/o an Intellectual Disability and their families based on their individual and family concerns and interests.
- B. Developing services and programs throughout the region that respond to the above individual and family interests and issues.

7. Flexible Funding by Autism Support Centers:

In some situations, the Autism Support Centers may be responsible for administering flexible funding allocations at the discretion of DDS Area Offices. In this circumstance, Autism Support Centers are responsible for following the Flexible Funding processes outlined in Section VII of this manual.

8. Autism Waiver Program Broker Service:

The Children's Autism Waiver Program is a statewide program that helps young children, birth through age 8 with autism spectrum disorder through the use of an intensive set of in-home supports and services. This Program provides one-to-one behavioral, social and communication-based interventions. The Children's Autism Waiver Program is unique in that it is a self-directed support program, meaning that families play a significant role in hiring staff and identifying the services they wish to have in place for their child.

Every Autism Support Center has designated Support Brokers who work with a DDS Autism Clinical Manager (assigned by the Autism Division in Central Office) to work with families enrolled in the Autism Waiver to develop an in-home support plan and decide on other complementary services. The Autism Support Center is charged with providing the appropriate level of supervision for the Autism Support Brokers on staff. More information about the role of Autism Support Brokers can be found in the Autism Support Broker Manual, a separate document.

Program Requirements and Expectations:

- The Autism Support Center must have a main office site that is centrally located and accessible to the majority of the families it serves. It must also make local arrangements with community resources (i.e. libraries, schools, community agencies, etc.) for space to hold family meetings and trainings as needed to create equal access for families across the area.
- Autism Support Centers must create access and be responsive to cultural and linguistic communities in their geographic areas.
- Autism Support Centers must be open and responsive to family needs, including evenings and weekends.
- Staff need to be mobile and able to meet families in their homes and local communities.

Data and Reporting Requirements:

The Autism Support Centers are expected to submit the Autism Support Center Semi-Annual Data Report twice a year to the Regional Family Support Director, Regional Autism Coordinator, and the Autism Division in Central Office.

Family Stabilization Service Rates:

Per Chapter 257 of the Acts of 2008, the Executive Office of Health and Human Services (EOHHS) has responsibility for establishing rates of payment for social service programs purchased by the Department of Developmental Services. The following program comes under Chapter 257 and regulated rates of payment have been established by the Executive Office (EOHHS):

Monthly Accommodation Rate for Autism Support Center FTE's:

Rates are periodically reviewed and are subject to change. Any changes to the Family Stabilization regulation, **101 CMR 414.00**, are posted by the Executive Office of Health and Human Services and can be found via the following link: <http://www.mass.gov/eohhs/gov/laws-regs/hhs/purchase-of-service-rates-for-social-services.html>



**Harvest Festival, sponsored by Northeast Arc & the Autism Support Center,
Brings out Lots of Families!**

D. Intensive Flexible Family Support Services (IFFS)

Service Description:

The primary goal of Intensive Flexible Family Support programs is to help support families with one or more members with a disability who are experiencing significant challenges, which are causing the child/individual to be at risk of out-of-home placement. This is a time-limited (6 to 12 months) and goal-oriented service providing more focused and intensive supports in response to identified areas of need and difficulty, and to build family capacity to support their child at home.

IFFS is purchased as a discrete program service at both the Regional and Area Office level. It is a closed referral program through the local DDS Area Offices. Children and young adults who receive services through an IFFS program will meet the following criteria:

- The individual has been determined eligible for DDS services.
- The individual is between 3 and 22 years of age and is living in the family home.
- The individual is at risk of out-of-home placement due to the family's difficulty in meeting the child's extensive care needs and/or the family is experiencing excessive stress or destabilization.
- The individual is not under the custody of the Department of Children and Family Services (DCF) or the Department of Youth Services (DYS). Children in a pre-adoptive home may be eligible for participation in this service.

Service Elements:

IFFS Programs are expected to provide the following enhanced and specialized services using a family-centered approach:

- A. Complete written assessments of the individual and/or family to identify needs and strengths and establish written agreed upon goals and objectives.
- B. Development of a family support plan which outlines specific goals, objectives, time-lines and responsible parties.
- C. Actively engage families and provide intensive staff assistance and supports to address identified needs and work on established goals and objectives to enable the individual to remain at home. This will include discussion with the families regarding potential services, counseling, medical or other generic resources that will support the child remaining at home and assist them to navigate the service system.
- D. Identification and facilitation of referrals and access to other services that may be of benefit to the child and family including generic services, such as housing, transportation, entitlements, and other community resources.
- E. Assist the family in the coordination of services that may include medical services, therapies, behavior training, educational services, etc.
- F. Education, training and referral for parents/caregivers in how to better care for their family member and enhance their capacity to meet the individual's physical, behavioral, medical and emotional needs.
- G. Provide monthly written progress notes addressing both the written and agreed upon goals and objectives, including any significant events during that month.
- H. Work in close collaboration with the Area Office to review progress on a quarterly basis at a minimum, and assist in developing plans to help a family transition to less-intensive supports when specific identified goals have been met and/or increased stability has been achieved.
- I. Provide administration of a pool of flexible funding that may be available to address the extraordinary support needs of families, on a one-time basis, who are receiving services in this Program. These individual flexible funding allocations for families will be communicated with the Area Office following the process described in Section VII of this manual.

Staffing Requirements:

- Program staff should have a Bachelor's Degree or, in the alternative, three years' experience working in the Human Services field.
- Program staff should have experience working in the human services field and/or experience working with families of children and young adults with intellectual and developmental disabilities, in particular individuals with behavioral challenges.
- Are knowledgeable about clinical resources including services through the Children's Behavioral Health Initiative.
- The program will have qualified staff members who are knowledgeable about public benefits, entitlements, and generic resources available in the geographical areas they cover.



Regional IFFS program successfully assisted family through the application process with Habitat For Humanity and provided other needed supports, culminating with the family moving to their new accessible home in Fitchburg.

Programmatic Requirements and Expectations:

- Each IFFS Program needs to have bilingual capacity (as it relates to the geographic area being served) or the ability to partner with an agency that provides interpretation/translation services.
- Services need to be provided on a flexible schedule to be responsive to the specific needs of families, including week-ends and evenings.
- Staff need to be mobile and able to meet families in their homes and local communities.

Data and/or Reporting Requirements:

IFFS Programs are required to submit the *Intensive Flexible Family Support Programs Annual Data Report*. (See Section XII, IFFS)

Family Stabilization Services Rates:

Per Chapter 257 of the Acts of 2008, the Executive Office of Health and Human Services (EOHHS) has responsibility for establishing rates of payment for social service programs purchased by the Department of Developmental Services. The following program comes under Chapter 257 and regulated rates of payment have been established by the Executive Office (EOHHS):

Intensive Flexible Family Support Services: Daily Enrollment Rate

Rates are periodically reviewed and are subject to change. Any changes to the Family Stabilization regulation, **101 CMR 414.00**, are posted by the Executive Office of Health and Human Services and can be found via the following link: <http://www.mass.gov/eohhs/gov/laws-regs/hhs/purchase-of-service-rates-for-social-services.html>

E. Medically Complex Programs

Service Description:

Medically Complex Programs provide a family-driven model of care which supports families with children and young adults living at home who have significant cognitive, physical, and complex health care needs. The goal is to provide comprehensive wrap-around supports, which consist of specialized case management activities that help families integrate the variety of resources and supports they are receiving in order to care for their family member at home.

This Program complements and is supplemental to other MassHealth, state plan and third party insurers and provides vital assistance to families who need help in coordinating all of the in-home care they receive. This program offers an array of support options to families (parents and siblings) to keep their family member at home and allow for a meaningful quality of life for all, and helps to prevent out of home placement in a pediatric nursing home or residential school.

Medically Complex Program services are purchased as a discrete program service at the regional level. It is a closed referral program through the local DDS Area Offices. The individuals and families who receive these services should reflect the broad mix of multi-cultural and multi-lingual populations across the state.

Individuals and their families who receive these services will meet the following criteria:

- The child/young adult has been determined eligible for DDS services and has complex medical and developmental needs. {Note: Once individuals turn age 22 they must be determined to meet DDS adult eligibility}.
- Children starting at age 3 through young adults up to age 25, who are engaged in transition planning to adult services.
- Children and young adults living at home with parents/family who are actively involved in the provision of care.
- Children and young adults who may be at risk of out-of-home residential placements in a pediatric nursing facility due to the complexity of their care and support needs.
- Children and young adults meet one or more of the following criteria that have been established to define medically complex:
 - Presently receiving in-home nursing or eligible for MassHealth continuous nursing services (CNS) as authorized through the Community Case Management Program;
 - Diagnosed with chronic, potentially life threatening medical condition(s) required skill nursing assessments and daily technological and/or medical interventions from trained family, support staff, or health professionals.



A Family Picture from the Annual Christmas Party sponsored by Family Partnerships, the Medically Complex Program in Central MA. Family Partnerships (Shriver Clinical Services) is one of five DDS-funded Medically Complex Programs in the state.

Service Elements:

- A. All families referred to the Program should have the following services available to them:
- Information & Referral, which includes linkages to and coordination with other services and resources.
 - Assessment of family needs and capacity using a “strength-based” approach.
 - Communication with families and provision of emotional support, with opportunities for families to support one another through formal and informal networking, which may include trainings, workshops, etc.
- B. Provide comprehensive Service Navigation to identify wrap around supports for families caring for children/young adults with multiple, complex, severe health care and developmental needs including:
- Complete an assessment to determine the needs of individual and family.
 - Develop a comprehensive Family Support Plan for each individual and family on an annual basis.
 - Provide intensive case management and planning to identify, provide, help arrange or facilitate supports for families including but not limited to: interagency/community funding; in-kind community donation of services; identification of additional in home medical supports, medical equipment and advocacy; access home/vehicle adaptations; develop community inclusion opportunities; and school collaboration.
- C. Provide comprehensive Service Navigation for transition age/young adults up to age 25 and their families designed to offer specialized expertise and provide resource information specific to the individual’s medical challenges and supports that will be helpful in the transition planning process to adult life. This may include the following array of services as needed and in partnership with Area Office staff:

- Support and guidance to individuals and families during the transition planning years, including participation in the individual's service planning team meetings as needed (IEP, ITP, ISP). This includes supporting families in identifying both generic and other specific supports for individuals who are medically complex that are turning 22 and will continue to live at home with family. When a family supports a medically complex individual in their home, there is an expectation that, whenever possible, consideration be given to providing an enhanced package of family supports.
 - Assist individuals and families to access all services/benefits they are entitled to or eligible for, by specific age limits (e.g. 18) or within the time-frames and parameters stipulated by the different benefit programs and services, including government benefits.
 - Share ideas and experiences from other families about different possibilities for day/employment programs, transportation, in-home supports, medical services, adaptive equipment, legal issues, etc.
 - Help with problem-solving in the planning and delivery of adult services as it relates to the specific complex medical and support needs of the individual.
- D. Provide training for families and/or share information about relevant training opportunities.
- E. Administer a pool of flexible funding to address the unique support needs of families receiving services in this Program that are not covered by MassHealth, insurance or other sources. These individual family allocations decisions will be communicated with the Area Office according to the procedures outlined in Section VII of this manual.
- F. Provide time-limited consultation by sharing expertise, guidance and resources to DDS Service Coordinators, other Area Office staff, and Family Support Provider Agency staff who may be working with individuals with medical challenges and their families who may or may not meet the criteria for the Medically Complex Program services, to help build knowledge and develop capacity.
- This consultation can occur on an individual basis or in group settings through trainings.
 - This consultation can also be provided to families of children from birth to age 3 and/or Early Intervention staff to assist them in accessing services and to facilitate the transition from Early Intervention programs.
- G. Create a family-to-family network for participants who transition from receiving intensive service navigation to enable them to maintain connections and communication for ongoing support and information-sharing.

Program Requirements and Expectations:

- Each Medically Complex Program needs to be available and responsive to families with different cultural or linguistic needs.
- Services need to be provided on a flexible schedule that includes weekends and evenings, to be responsive to the specific needs of families.
- Staff need to be mobile and able to meet families in their homes and local communities.

Data and/or Reporting Requirements:

The Medically Complex Programs are required to submit the Medically Complex Programs Annual Report each year to the Regional Family Support Director.

Family Stabilization Services Rates:

Rates Per Chapter 257 of the Acts of 2008, the Executive Office of Health and Human Services (EOHHS) has responsibility for establishing rates of payment for social service programs purchased by the Department of Developmental Services. The following program comes under Chapter 257 and regulated rates of payment have been established by the Executive Office (EOHHS):

Medically Complex Programs: Monthly accommodation rate per enrollee

Rates are periodically reviewed and are subject to change. Any changes to the Family Stabilization regulation, **101 CMR 414.00**, are posted by the Executive Office of Health and Human Services and can be found via the following link: <http://www.mass.gov/eohhs/gov/laws-regs/hhs/purchase-of-service-rates-for-social-services.html>



FELIZ NAVIDAD! from one of the Family Bridges families
(the Medically Complex Program in Western MA) Holiday Event!

F. Family Leadership Programs

Service Description:

The Family Leadership Program is designed to provide education, leadership training and mentoring for families with children and adults with disabilities living in the community. One goal of these activities is to provide information on best practices and opportunities to support individuals and families to fully participate in all aspects of community life. A key feature of this program is that all the family leadership training and mentoring is developed and provided by family members who have a child or adult family member with a disability. One vehicle for family leadership development is the sponsorship of a Family Leadership Series, but other ideas and activities are implemented in response to local needs.

This is a family support service provided in all of the DDS regions across the state. It is intended that there will be coordination and collaboration across all of the Regional programs funded.

Eligibility for Family Leadership Programs:

Families with children or adult family members with disabilities are able to access many of the training, educational and mentoring opportunities offered by the Family Leadership Program. Due to the intensive nature of the Family Leadership Series, there is an expectation that priority be given to families who are (or likely would be) eligible for DDS. If spaces remain, then the Series can be opened up to families who are being served by other agencies such as DMH, MCB, DPH, etc. Although it is not expected that Family Leadership Coordinators confirm DDS eligibility, it is hoped that families who have not yet applied will be encouraged to do so. If a family is served by another agency, Family Leadership Coordinators will explain the portions of the Series that may not feel as relevant to them, so the family has appropriate expectations. Also, families being served by other agencies are not eligible for respite funding through DDS, so these resources would need to be pursued by the agencies supporting those families.

Service Elements:

- A. Through the family leadership training series and other opportunities, provide education and support to assist families and individuals to develop leadership skills and to understand policy-making at the local, state and federal level. A common curriculum is used across all of the regions.
- B. Offer information and education about “best practices” to support full participation in all aspects of community life for individuals with disabilities, and assist families in creating a vision for their family member to lead a full and productive life in the community along with a process to work toward achieving that vision.
- C. Provide mentoring opportunities to enable families and individuals to move into leadership roles and activities.
- D. Family Leadership programs work with families to reduce barriers that prevent families from attending training and educational opportunities offered
- E. Each Family Leadership Program is expected to develop a plan of training and other activities for the fiscal year to submit to the Regional Family Support Director. This plan should be based on family interests and developed in collaboration with DDS and other family support providers and community agencies.
- F. The Family Leadership Programs actively work in partnership with DDS Regional and Area Offices to sponsor additional trainings and forums to advance the above goals, as well as to offer opportunities for families to provide substantial consultation to DDS and other state agencies as part of the requirements of Chapter 171 of Acts of 2002.

G. The Family Leadership Programs are able to inform families of other educational opportunities and generic resources in their communities.

Program Requirements and Expectations:

- The Family Leadership Series and other family trainings must be accessible to families across the region.
- All training, educational and mentoring programs for families must be responsive to the cultural and linguistic communities in the designated geographic area.

Data and/or Reporting Requirements:

The Family Leadership Programs are required to submit the Family Leadership Program Annual Report each year to the Regional Family Support Director. **(See Section XII)**



Central MA Family Leadership participants visit the Massachusetts State House!

Massachusetts Department of Developmental Services

Section: VII - Individual Flexible Funding Allocations

A. Principles

Individual flexible funding is an important and integral resource provided within the broad array of other family support services offered through Family Support Centers and other specialized programs. It's expected that Service Navigators at the Family Support Centers are building relationships with individuals/ families and working with them in planning and monitoring the use of flexible funding allocations, along with their role in helping families access all other relevant resources and services, both at the state and local level. It's also important that this process supports the Department's articulated goals and principles of family support. As the Department implements a statewide process for the administration of flexible funding allocations, it's important to continue to provide flexibility, family choice and respect, timeliness, along with a recognition of the expertise of families regarding what will help them best provide for their family member.

➤ Flexibility

Area Offices and family support providers should support the flexibility found in the Allowables/Disallowables (section VII. C) in addressing individual and family needs. Families are the most knowledgeable regarding their family members and are in the best position to know what will best help them provide for their family member with a disability. The Allowables List is not viewed as exhaustive so families may request consideration of unique or individualized items or options which meet their needs. Questions can also be directed to the Area Director and/or the Family Support Director in the region.

➤ Choice

Individuals and families should have choice in how they receive their family support allocations based on the three different approaches made available by Family Support Centers and Programs. Some individuals or families may prefer to be **reimbursed** for expenses that they incur related to their family member's disability. Others may prefer to have a Family Support Provider Agency pay for goods and services on their behalf. This option is referred to as a **direct provider agency payment**. A third option is to receive family support allocations directly in the form of a **stipend**. These options enable families to tailor their purchases and supports in a way that is most responsive to their needs and circumstances.

➤ Predictability

Flexible funding allocations should be predictable for families from year to year unless there are significant changes in the individual/family circumstances which may result in considering an increase or decrease. Major budget changes may at times also impact the family support account. This predictability helps families to prioritize their needs within their expected allocation, rather than making numerous requests within a Fiscal Year, thereby increasing both the effectiveness and efficiency of flexible funding. Generally this support should be something families can count on!

➤ Accountability

Everyone involved in the utilization of state funds for individual flexible funding allocations needs to be accountable in ensuring that all policies, procedures and regulations related to this use of state funding are followed. These funds cannot be used for any purpose that may directly or indirectly

jeopardize the integrity of the program, or any activity which places the individual at physical or medical risk.

➤ **Consistency**

There needs to be consistent implementation across the state in terms of the principles, process and administration of flexible funding allocations to families. Area Offices and family support agencies should not impose additional restrictions or rules beyond those that are found in Section VII of this Family Support Program Manual and Guidelines.

➤ **Simplicity**

The process for administering flexible funding needs to be as simple as possible while meeting requirements, or its value will diminish. The administration should not be burdensome to the family or the provider, but needs to maintain reasonable safeguards to ensure good stewardship of Family Support funds, as outlined in Section VII of this manual.

➤ **Equity**

Individual flexible funding allocations should be fairly available, accessible and distributed to individuals/families across the state. These allocations should be based on an assessment of individual/family needs and the availability of funding. When families are identified as needing an allocation, the Department has established \$750 as a target minimum allocation, to be used as a starting point in planning with families when resources are available to do so.



B. Program Integrity: Authorizing, Reporting and Monitoring of Flexible Funding

This section provides an overview of the required processes for communication, reporting and tracking to promote consistent practices in the administration, implementation, and monitoring of flexible funding. This is intended to ensure clear expectations between the Area Office, Family Support Program staff, and individuals and families. These systems create a framework to support the principles of accountability and consistency and ensure program integrity and the effective stewardship of public funding.

Note: All flexible funding allocations administered by Family Support programs should be contracted using service code 3779.

Families may be able to receive their flexible funding allocation in the following ways:

- *Reimbursement to families* from the family support provider for expenses incurred for allowable services and goods;
- *Payment directly to a vendor* by the family support provider for specific allowable goods and services requested by the family;
- *Direct payment to families* in the form of a stipend for purchase of allowable goods and services.

These options enable families to tailor their purchases and supports to best meet their needs. A *Flexible Funding Expenditure Plan* must be completed in order for an individual/family to receive a funding allocation. This Plan is required even if an individual has an Individual Support Plan (ISP) or Family Support Plan.

These guidelines and procedures apply to flexible funding that is administered by Family Support Centers, IFFS and Medically Complex Programs. The Agency with Choice and Participant Directed Programs have different guidelines. Families who are participating in Agency with Choice, Participant Directed Programs, the Autism Waiver Program, and the DESE/DDS program are not eligible for Family Support allocations.

The Regional Family Support Director should be consulted when there are questions about flexible funding administration.

AUTHORIZING FLEXIBLE FUNDING ALLOCATIONS:

1. AUTHORIZING REGULARLY OCCURRING/ANNUAL ALLOCATIONS:

A. Area Office and Family Support Center staff will meet prior to the start of the Fiscal Year to identify the individuals/families who receive regularly occurring/annual allocations, to confirm who will receive an allocation for the following Fiscal Year. A roster will be developed of the individuals/families and their respective funding allocation for the upcoming year. This roster will be reviewed and updated as needed in the regularly scheduled program review meetings between the Area Office and the Family Support Centers.

- Subject to appropriation, individuals/families who have received allocations in the current fiscal year will continue to receive this level of funding in the next fiscal year unless it was a one-time expenditure, there are changes in the circumstances of the individual/family that would impact access to this funding, or the individual/family indicates they do not need this funding resource.

- Family Support Center staff should be building relationships and working with families in planning and monitoring the use of flexible funding allocations.

B. Individuals/families will be notified around the beginning of July of their funding allocation for the upcoming year. This notification can occur as part of the communication process for completing the Flexible Funding Expenditure Plan (Expenditure Plan) between the Family Support Center and family; or through a phone call or email sent to the family.

C. The Family Support Center will complete the Expenditure Plan with the family in a timely way so families can access funding, ensuring all necessary signatures and will then forward this to the Area Office designee. It's expected that all Expenditure Plans will be completed and submitted by September 1st to the Area Office designee. Once the Expenditure Plan is submitted to the Area Office, funds may be expended. The Family Support Center will retain a copy of the Expenditure Plan as part of the record for each individual/family, and will also send a copy of this plan to the family.

2. AUTHORIZING ALLOCATIONS FOR FAMILIES IDENTIFIED THROUGHOUT THE FISCAL YEAR:

Individuals/families can be identified throughout the year who will benefit from flexible funding resources and an allocation can be assigned based on available DDS funding.

A. When Needs Are Identified by the Family Support Center:

- A. The Family Support Center will communicate to the Area Office Designee the name of the individual/family, the identified need, and a recommended allocation amount. It will be noted if this is a one-time funding request or a request for an ongoing allocation. Centers may use the standard Family Support Center Flexible Funding Request form for this purpose.
- B. The Area Office Designee will review the request and provide approval or denial. Verification of the individual's DDS eligibility will be completed prior to approval. The Area Office Designee will communicate their decision to the Family Support Center by email or by phone with a follow-up email, so they can follow up with the individual/family in a timely way.
- C. Upon approval, the Family Support Center will complete the Expenditure Plan in a timely way, but no later than 30 days from date of request, and submit to the Area Office Designee with required signatures. Upon submission of the Plan, funds can be expended. (Attachment D, Section 11)

B. When Needs Are Identified by Area Office staff:

- 1. Using the Family Support Center Flexible Funding Request form (see Attachment C), the DDS Service Coordinator will communicate to the Area Office Designee the name of the Individual/Family, their identified need, and recommended allocation. It will be noted if this is a one-time funding request or a request for an ongoing allocation.
- 2. The Area Office Designee will verify DDS eligibility and approve or deny the funding request.
- 3. If approved, the Flexible Funding Request Form will be forwarded to the Family Support Center who will contact the family and complete the Expenditure Plan in a timely way, but no later than 30 days from the date of request, (inclusive of all necessary signatures), and submit this to the Area Office Designee. Upon submission of the Plan, funds can be expended.

C. In Emergency Situations:

Periodically there are situations that arise when individuals/families need flexible funding resources in an emergency situation. These requests need to be reviewed in a timely way by the Area Office Designee, verification of the individual's DDS eligibility confirmed, and a written decision communicated to the Family Support Center to approve funding. In these situations funding can be made available within a very short period of time. However, an Expenditure Plan is still required,

even if completed after the funding has been made available, and a copy sent to the Area Office Designee.

3. CHANGING FLEXIBLE FUNDING ALLOCATIONS WITHIN THE FISCAL YEAR:

- **Increases:** If a family requests an increase to their original allocation within the same Fiscal Year, the Family Support provider should contact the Area Office designee for written approval. If an increase is approved, it should be added to the Expenditure Plan as an “Increase within FY,” and its intended purpose listed in the “Increase” column. The amended plan should be sent to the Area Office designee to be placed in the individual’s file.
- **Decreases:** If a family is not going to use their full allocation, the Family Support provider should amend the Expenditure Plan to reflect the decrease (as a “Decrease within FY”) and adjust accordingly in the “Decrease” column. The amended plan should be shared with the Area Office designee to be placed in the individual’s file.
- **Changes in purpose:** If a family decides to use their funding allocation for a different purpose than originally planned, as long as the new purpose is an Allowable Expense, the Family Support provider will amend the Expenditure Plan by adding increases and decreases to categories, and keep it in their file, to be made available to the Area Office.

4. ADMINISTRATION OF FLEXIBLE FUNDING BY MEDICALLY COMPLEX AND IFFS PROGRAMS:

Medically Complex and IFFS Programs are contracted to administer a small pool of flexible funding, to be provided to address the unique support needs of families currently receiving services through these programs. Flexible funding from these programs are intended to be supplemental in nature, and are limited to the time period they are enrolled and receiving these specific program services. Therefore, based on their needs, families in the Medically Complex and IFFS programs may also receive a flexible funding allocation from their local Family Support Center as authorized by the Area Office. In this circumstance, the Area Office is responsible for coordinating these two allocations to ensure that the funding is being used for different purposes. For example, a family may receive flexible funding from their Family Support Center for ongoing respite, and may also receive one-time flexible funding from the Medically Complex Program for the installation of a ramp or uncovered medical supplies. If a family is receiving a regular allocation from their Family Support Center, the Area Office should inform the Medically Complex or IFFS Program at the time of referral.

All policies and procedures for Flexible Funding administration by Family Support Centers applies to Medically Complex and IFFS Programs with the following differences:

- These programs need to maintain a roster of families receiving flexible funding allocations each Fiscal Year, to be shared with the Area or Regional Office designee at quarterly review meetings. Allocations will be determined throughout the year, based on the needs of the family and availability of resources.
- Except in emergency situations, when program staff identify a need within a family, they must communicate to the Area Office Designee (cc’ing Regional Office if Regional contract) with the name of the individual/family, the need, and a recommended allocation amount. Upon receiving written approval, program staff will complete and submit a Flexible Funding Expenditure Plan to the Area Office, after which funds may be expended.
- In emergency situations, these programs have the discretion to provide resources to respond to needs around health and safety, and communicate with the Area Office within a week of disbursing the funds.

SPECIAL CIRCUMSTANCES IN FLEXIBLE FUNDING ADMINISTRATION

1. PRIOR APPROVAL REQUIREMENTS AND PROCESSES: Prior Approval by the Regional Office is required for allocations above \$3000 and for Home/Vehicle Modifications above \$1000 in cost. Details appear below.

A. Flexible Funding Requests above \$3,000.00 must be approved by the Regional Director or Designee. In situations when an Individual receives a flexible funding allocation above \$3000.00 from one year to the next, this Prior Approval Process must be completed annually. This Prior Approval also applies when multiple flexible funding allocations issued to an individual/family total over \$3,000 in the same fiscal year. It also applies when an individual/family receives flexible funding from multiple Family Support programs, such as Medically Complex, IFFS and Family Support Centers. It does NOT apply when there is more than one individual with a disability in the family household so long as each individual is receiving less than \$3000 in flexible funding.

- The Service Coordinator should complete the Prior Approval form, including the total amount of flexible funding requested, a brief rationale describing the needs of the individual and family, and how these additional funds will be used to address those needs. The form may be completed in partnership with the Family Support provider, but needs to be reviewed and submitted by the Service Coordinator. This form, along with any other pertinent information (such as the Family Support Plan, etc.) must be completed and submitted in advance to the Area Office Director/Designee for review and recommendation. Upon approval by the Area Director/Designee, this information must be forwarded to the Regional Director/Designee for approval and signature.
- The Regional Office notifies the Area Office of its decision and sends the form back to the Area Office, who notifies the Family Support Provider and the family.

B. Vehicle or Home Modification Requests: Vehicle and Home Modification Requests that exceed \$1000 require Prior Approval from the Regional Office. In these circumstances, the Vehicle or Home Modification Prior Approval Funding Request Form will be completed and submitted to the Area Office Designee, along with the required three bids for home modification requests. If it is not possible to secure three bids, an explanation must be included on the form.

- The request will be reviewed by the Area Director and then sent to the Regional Director/Designee for his or her approval. Their signatures are required to constitute approval of this expenditure.
- Verification of completion of the home or vehicle modification will be made in person by the Service Coordinator or Area Office designee and noted on the Vehicle or Home Modification Prior Approval Funding Request Form in the individual's Area Office file.

2. USING FLEXIBLE FUNDING FOR CENTER-SPONSORED ACTIVITIES:

In some situations Family Support Centers have been allocated flexible funding resources to sponsor group social/recreational activities that are designed to meet the expressed needs of individuals.

- A. For more specialized small group activities that are more time-intensive, such as a school vacation program, instead of Flexible Funding Expenditure Plans, the Family Support Center must keep a confirmation of attendance for each individual whose flexible funds were used for this activity, and this should be retained for auditing purposes.
- B. For large group social activities, the Family Support Centers should keep a list of events with dates, and the names and number of attendees, and have this available for review.

3. FLEXIBLE FUNDING FOR FAMILIES PROVIDING ADULT FOSTER/FAMILY CARE (AFC) IN THE FAMILY HOME:

Since AFC is a MassHealth funded program, DDS cannot use funding to provide *duplicative services* to individuals/families enrolled in AFC. Flexible funding for families providing AFC in the family home is only allowed for specific purposes and in circumstances that will address:

- an identified need of the individual as determined by the person's planning team
- and will be of direct benefit to the individual.

Examples of allowable goods or services may include fees for the individual to attend an adult education course, travel training, wellness or fitness groups, purchase of assistive technology or adaptive footwear. Uses that would not be allowed include: respite, payment of utility bills.

In reviewing Flexible Funding Expenditure Plans, the Area Office will note which individuals receive AFC services and will ensure that the Expenditure Plan does not fund duplicative services to those offered by AFC. There is specific guidance that defines what other DDS services may be utilized in this circumstance, which can be found in **Section VII E** of this manual.

REPORTING AND MONITORING OF FLEXIBLE FUNDING ALLOCATIONS

1. Family Support Centers and Programs must develop written internal policies and procedures for the administration of flexible funding allocations which is distributed to staff. These written procedures will be made available to DDS upon request.
2. Family Support Centers will maintain a tracking system of all approved allocations that includes information on current expenditures to date, remaining balance, and purpose of the expenditure, to be submitted with monthly billing for flexible funding on the Invoice Documentation Form.
3. All Family Support programs will maintain back-up documentation to justify amounts invoiced and paid each month. Back up documentation will be made available to DDS for review upon request.
4. Monthly, DDS Contract staff will be reviewing Invoice Documentation Forms to ensure that total amounts are aligned with total billing. Quarterly, Area Offices will review some corresponding expenditure plans to ensure that what has been billed correlates with Flexible Funding Expenditure Plans. At least annually, DDS will review a sample of Expenditure Plans including backup documentation, and verification of receipt of the supports/goods/services by the individual/families.
5. Area Office and Family Support Center staff will meet at least quarterly to review all flexible funding allocations and expenditures, and compare total expenditures to funding for the fiscal year.
6. The Medically Complex and IFFS program should meet with the Area Office or Regional Family Support Director (depending on the source of the contract) on at least a quarterly basis to review all program activities. At this time a ledger of flexible funding expenditures should be produced and reviewed.

C. Allowables/Disallowables

All family support is subject to appropriation, and all family support allocations are based upon existing resources. Family support allocations shall be used to supplement assistance available to the individual or family through other state or federal resources and generic funding sources. DDS funds shall not supplant other available resources.

When reviewing family requests to utilize flexible funding allocations, it is important to revisit the Guiding Principles of Family Support. Family support should respond to family identified needs and direct input from individuals with disabilities. It's important for families to be empowered and supported in their choices of how they use their current family support allocation unless their requests fall into restricted categories. Additional restrictions or limits on these allowable categories should not be imposed, and if there are questions or concerns, they should be discussed with the Area Director and/or the Regional Family Support Director.

CATEGORIES OF ALLOWABLE EXPENDITURES (Section a) provides a description of the categories of expenditures for which family support allocations may be used, and offers examples of items that may be appropriate expenses with these funding allocations. This list and the specific examples are not intended to be exhaustive. If families and individuals identify other individualized and unique support options this should be discussed in advance with DDS Area Office staff for consideration and approval. It is the intent of these guidelines to emphasize the importance of flexibility in honoring family choices in how they use their funding, so long it meets the needs of the individual or family and does not conflict with the list of the disallowable expenditures.

When stipends will be used for the payment of staff supports (such as respite), it is important to inform families/individuals that these payments may be subject to the Internal Revenue Service (IRS) regulations on Household Employees (www.irs.gov).

Many of the allowable services listed below are also services offered through the Department's Home and Community Based Waiver Programs for adults, although the definitions may be slightly different. It's expected that adults who are enrolled in one of the Department's Adult Waiver programs will first utilize services available to them through the Waiver program prior to using state funding in the form of a flexible funding allocation to purchase a similar service.

CATEGORIES OF DISALLOWABLE EXPENDITURES (Section b) provides a description of the categories of expenditures that are not allowable with flexible funding. Questions regarding appropriate expenditures for family support allocations should be referred first to the DDS Service Coordinator or Area Office Director/designee. The Regional Family Support Director should be used as a resource by DDS staff, families, and Family Support Provider staff if guidance or clarification is needed about allowable expenses with family support allocations.

a. CATEGORIES OF ALLOWABLE EXPENDITURES

The following are categories of allowable expenditures that families can prioritize to use within their existing flexible funding allocation:

1. Respite Support

This category includes Respite and Intermittent Care services, both of which provide a break in caregiving responsibilities for families and caregivers, either on a regular or occasional basis. These services can be provided in the individual's home, in the community, or in a variety of out-of-home settings. Allocations can also be used to pay for site-based respite programs. Respite may be provided for varying lengths of time depending on the needs of the family and available resources. This support can also provide opportunities for the individuals to develop more independence and skills as well as provide opportunities for enjoyment and socialization with peers. These services often reduce family/caregiver stress and thereby help preserve the family unit, support family stability, and prevent lengthy and costly out-of-home placements. *Depending on the amount paid to a care provider in a given year, there could be tax implications for the family if they are paying the caregiver directly. Information on this should be shared with families.*

2. Recreational & Social Inclusion Activities

Activities or supports aimed at increasing and/or enhancing the social integration of the individual with a disability. Examples can include fees for community recreation programs, scouting programs, yoga or dance classes, and payment of support staff to assist the individual to fully participate in recreational/social activities. Funds may also be used to contribute toward the cost of recreational opportunities for the family as a whole, such as a family membership at the local YMCA or fees for family recreation, if this enables the family member with the disability to participate in these activities. .

- **CAMPS** – Funding for summer camps should be paid in the fiscal year that the camp actually occurs. An exception would be if a deposit or tuition is required in the previous fiscal year for ALL campers (not just for DDS participants) in order to reserve one's slot in camp.
- **ANNUAL MEMBERSHIPS** - In reference to annual memberships to the YMCA and other community organizations, these come due at all times during the fiscal year. It is permitted to pay for yearly memberships when they come due even when the membership crosses fiscal years.
- **FAMILY VACATIONS** – Flexible funding is not intended to pay for family vacations, but funding may be used to pay for specialized support needs related to the individual's disability, so that they may participate in a family vacation. This could include respite staff support, or the cost of accessible transportation, beach wheelchair rentals, or other accommodations.
- **INDIVIDUAL VACATIONS** - Adults may use their existing funding allocation to contribute towards the cost of going on a vacation which provides the supports they need to go on a trip without their family.

3. Child Care

Families may choose to use their existing allocations to cover a portion of the cost for after-school programs, child day care costs, or a family's share of such costs for the individual with a disability. Resources from school districts and other resources should be used first. Funds may be used to care for a sibling(s) in order for the parent(s) to spend time alone with the individual or his/her siblings, or when the family must attend to the family member with the disability due to health or behavioral issues.

4. Home Management Support Services

This service consists of assistance with or the performance of general household tasks, such as routine household cleaning, snow removal, meal preparation, and management of finances, which enable the family to provide for the individual with a disability when the caregiver requires assistance to manage the home and care.

5. Short-Term Emergency Needs

Short-term emergency assistance enables families to continue to provide care for the individual with a disability. This can be provided on a one-time basis, not to last longer than **3 months within a Fiscal Year**. All other resources should be explored so that DDS is the payer of last resort. Examples of short-term emergency needs may include food, short-term rental assistance to prevent homelessness, clothing, car rental, car repairs, or general household costs. Any extensions and/or repeated requests for additional emergency funding will require a team discussion involving at a minimum; the family, the family center navigator, and an Area Office representative. If a family support plan does not address this on-going need, it needs to be developed as part of an approved extension for continued use of funding for basic/emergency needs.

6. Specialized Evaluations and Therapeutic Services and Supports

Prior to using DDS funding for these services, **private insurance, MassHealth (including Children's Behavioral Health Initiative), and special education services should always be utilized first**. Services in this category can include access to evidence-based services such as occupational, physical, speech and behavior therapies by licensed professionals for the individual with a disability, and other counseling and therapeutic services, as long as the individual is not eligible for or has exhausted other funding sources for these services. As part of their ongoing planning process, it's important for Family Support staff to review and discuss with families the specific treatment plan and goals, and the effectiveness of these services. Other examples of approved uses may include costs for dental or medical care not covered by the family's insurance, including co-payments for medical appointments and medication. However, costs associated with private health insurance premiums and CommonHealth premiums are **not allowable**, and funds cannot be used to supplement MassHealth rates for medically necessary services.

7. Adaptive Equipment and Supplies

Prior to using DDS funding for these services, **MassHealth, private insurance, schools, and other resources should always be utilized first**. This category can include personal, adaptive equipment for the individual with a disability that is not covered by insurance. **Examples may include:** positioning boards, special chairs, water or hospital beds, etc.

Funding can also be used for other household equipment to meet the specialized support needs of the family member with a disability that is not covered by other sources. This can include an air conditioner, air purifiers, generators or home safety equipment, such as window locks, shower grab bars, door alarms, or an intercom for nap or night time monitoring.

- **COMPUTERS, TABLETS & OTHER ASSISTIVE TECHNOLOGY** – **MassHealth, private insurance, and school resources should be utilized first for assistive technology. Once other resources have been explored**, computers, tablets and other assistive technology for the benefit of the individual with a disability, may be covered in full or in part for the purposes of communication, social and educational enrichment, care coordination, and other disability related needs. This includes adaptive equipment for computers or specialized software.

• **PERSONAL SAFETY MONITORING DEVICES:** In circumstances when ongoing personal monitoring devices are being considered for safety purposes, there should be a discussion that considers the age and developmental needs of the individual in addition to safety, privacy and human rights. For example, a gps tracking device may be appropriate for a young child with limited safety skills and a history of elopement. Any personal safety device must meet the following criteria:

- Is being used to address a compelling safety need
- Is the least restrictive or invasive method which could limit or eliminate the risk
- There is consideration of a plan to teach skills which would mitigate the need for the restrictive device, or to evaluate the ongoing need for the restriction.

8. Specialized Nutrition and Clothing

Prior to using DDS funding, payment by **MassHealth and private insurance should always be pursued and utilized first**. This category can include special vitamins, specialized foods, and dietary supplements which are recommended by a health professional or are FDA approved, and which help the individual maintain optimum health as it relates to medical issues and nutritional needs. It can also be used for adaptive clothing or footwear, including expenses for clothing that need to be replaced frequently due to excessive wear and tear as a result of the individual's special needs.

9. Specialized Utility Costs

This encompasses supplemental heating and air conditioning costs specifically related to the disability needs of the individual, including additional expenses incurred with the use of generators in emergency situations.

10. Transportation

Includes gas (or mileage), and other travel related incidental expenses when extraordinary out-of-pocket expenses are incurred due to hospitalizations or to attend medical appointments as required to meet the individual's special medical/health needs. This could include rental of an accessible wheelchair van under certain circumstances.

Generally, using flexible funding to pay for transportation costs associated with other DDS contracts such as Day and Employment Services is not allowable. In certain circumstances, however, it may be determined that providing transportation through flexible funding provides a more cost effective and flexible transportation option that allows the individual to get to their work or day program. This might be in the form of reimbursing families for mileage, or fares for public transportation or rideshare services. In this circumstance, additional funding should be added to the flexible funding contract from the relevant DDS account (such as transportation or Turning 22), and it should not impact a family's existing family support allocation.

Reimbursement for mileage will be at the same rate that is established by the Commonwealth of Massachusetts, which is currently \$.45/mile. This rate can be found on www.mass.gov

11. Personal Growth and Enrichment Activities

These are services designed to assist individuals in acquiring, improving and retaining self-help, socialization and adaptive skills necessary to engage successfully in one's home and/or in the community.

This would also include participation in community activities that would enhance an individual's social capital, including developing relationships between people with and without disabilities. A

wide range of examples might include: travel training, social skills groups, computer classes, adult education classes, art classes, wellness and fitness groups, hobby clubs, etc. For questions about using DDS funds for participating in post high school educational or training programs, please refer to DDS Post High School Educational and Training Institutions -Interim Guidance (Fall of 2018).

Individuals may use their funding allocations to contribute towards a Person-Centered Planning process to develop a vision and a plan to achieve their goals. The choice of a planning facilitator would be up to the individual and family.

12. Family Training

This includes services which enable family members to gain the knowledge and skills needed to participate more fully in various aspects of caring for and supporting their family member with a disability, including learning the various techniques and strategies necessary to help the individual to progress. This may include payment for registration costs and fees for family members (including siblings) to attend local trainings and conferences that provides them with knowledge, skills and support to more effectively care for their family member with a disability. This does not include payment for lodging and travel.

13. Educational Consultation and Support

Funding can be used by families to obtain consultation, assistance and advocacy support with educational planning and programming for their child/young adult with a disability who is entitled to receive special education services. This may include helping to prepare families for Individual Education Plan (IEP) meetings as well as attending IEP meeting with families. Funding for this service is limited up to \$750.00 per year. This funding cannot be used to pay attorney fees or other legal fees related to educational appeals.

14. Vehicle Modifications

Family support allocations may be used to contribute toward the cost of vehicle modifications. The need for the vehicle modification must be the primary means of transportation for the individual, and specifically related to the functional limitation caused by the individual's disability. This can include funding for adaptations to a new van or vehicle purchased/leased by a family, which can be made available at the time of purchase or lease. This will accommodate the special needs of the individual and help offset the additional costs related to the modification.

Family Support staff should assist the family in exploring the availability of alternative funding sources such as insurance, civic organizations, fund raising, and other generic resources before requesting to use a family support allocation for a vehicle modification.

There is a Prior Approval Process for any vehicle modifications that exceed \$1000 in cost. This process is as follows:

1. The *Vehicle or Home Modification Prior Approval Funding Request Form* must be completed and submitted to the Area Director/Designee. This form shall detail the request for funding, consideration of other funding sources, and justify the need for the vehicle modification.
2. If the Area Director approves the Request and recommends funding, the Request is forwarded to the Regional Director/Designee for his/her final review, recommendation and signature.
3. Upon the Regional Director/Designee approval/disapproval, the Regional Office sends the signed copy back to the Area Office which notifies the Family Support Provider who will inform the family that the funding request has been approved/disapproved.

Examples of vehicle modifications for which family support allocations may be approved, include:

- Van lift
- Tie downs
- Ramp
- Specialized seating equipment
- Seating/safety restraint

Examples of funding requests, for which family support allocations shall not be approved, include:

- Contribution towards purchasing or leasing a vehicle
- Automotive Insurance costs
- Automotive Taxes (excise)

15. Home Modifications

Family support allocations may be used to contribute toward the cost of family home adaptations that will directly benefit the individual with a disability and relate to his/her health and safety. Family support funding shall only be used for renovations that will support the individual in his/her primary residence, and must specifically relate to the functional limitation(s) caused by the individual's disability.

Family Support staff should assist the family in exploring the availability of alternative funding sources such as insurance carriers, other state or federal funding resources, civic organizations, fund raising, and other generic resources before requesting to use a family support allocation for a home modification.

Family Support staff shall also explore utilization of appropriate portable modifications to accommodate changes in residence, size of person, and changes in equipment and needs.

There is a Prior Approval Process for any home modifications that exceed \$1000 in cost. This process is as follows:

1. The *Vehicle or Home Modification Prior Approval Funding Request Form* must be completed and submitted to the Area Director/Designee. This form shall detail the request for funding, justify the need for the home modification, and include three bids. If it is not possible to secure three bids, an explanation must be included on the form
2. If the Area Director approves the Request and recommends funding, the Request is forwarded to the Regional Director/Designee for his/her final review, recommendation and signature.
3. Upon the Regional Director/Designee approval/disapproval, the Regional Office sends the signed copy back to the Area Office which notifies the Family Support Provider who will inform the family that the funding request has been approved/disapproved.

Examples of home modifications for which family support allocations may be approved:

- Ramps
- Widening of doorways
- Bathroom modification
- Stair lift
- Yard fence

Examples of home modifications for which family support allocations shall not be approved:

- Modifications that have no direct impact on the functional limitations of the disability of the individual
- Additions to an existing home, including accessory apartments
- Remodeling solely for the purpose of increasing the value of the home

16. Other Approved Uses

Families may request unique or individualized items or options which would meet their needs and are not on the disallowable list. In these situations family choices should be strongly considered.

Some examples of what may fall in this category may include:

- **WASHERS AND/OR DRYERS** – In some circumstances, using flexible funding for the purchase of a washer and/or dryer, in full or in part, may be appropriate when, due to their disability, the individual has increased laundering needs and when use of a laundromat would create a logistical or financial hardship for the family.
- **SERVICE DOGS** - There are many types of service dogs. These dogs are individually trained to perform specific tasks for individuals with varying disabilities based on an assessment of the individual's needs. Given the costs involved with the purchase, training and care of a dog, other resources need to be explored to offset the individual family support allocation. This request must include an analysis of all these factors with a detailed breakout of costs. Even if approved, the decision may involve only covering some, not all of the costs.



b. CATEGORIES OF DISALLOWABLE EXPENDITURES

In addition to items that have been mentioned previously in this Manual, Family Support Funds shall not be used for the following:

General

1. Items or activities that have limited benefit to the individual with a disability. An example is a home modification which has no direct impact on the functional limitations of the person with a disability, or luxury items such as a swimming pool.
2. Any purpose that may directly or indirectly jeopardize the integrity of the program, for example, fraudulent use of funds, support for criminal conduct, or any activity which places the individual at physical or medical risk.
3. Any purpose that may unduly infringe on an individual's privacy, or that may violate their human rights.
4. Purchasing of items or services that are not allowed by state regulation, including the regulations of the Operational Services Division regarding lobbying for litigation against the Commonwealth.
5. The provision and purchase of services that are normally covered by other contracted DDS service codes, including but not limited to, residential supports outside of the family home, employment and day program services. Generally, transportation costs associated with other DDS contracts such as Day and Employment is not allowable except in certain circumstances as outlined in Allowable Category 10 (Transportation).

Medical

6. Payment for therapies, treatments or medications which are not evidence-based, including experimental and/or non-approved FDA (Federal Drug Administration) treatments or medications unless it is part of an approved clinical trial.
7. Costs associated with CommonHealth and other private health insurance premiums, nor can funds be used to supplement MassHealth or private insurance rates for medically necessary services.

Personal Expenses

8. Long-term financial assistance (greater than three months) to address basic needs such as the purchase of groceries, rent, mortgage, payment of utility bills, etc.
9. Payment for housing supports such as the principal on a mortgage, the down payment on a residence, or tax or other municipal bills on property.
10. Payments towards the purchase or lease of a vehicle, including insurance costs and related taxes.
11. Share of cost of family vacation and or housing rental.

12. College credit classes, and related registration, fees, books, meals, and education based residential housing. Funding cannot be used for out of state programs. See DDS Post High School Educational and Training Institutions -Interim Guidance (Fall of 2018).

Legal

13. Payment of an attorney or legal fees. Examples include fees related to trusts, immigration petitions or appeals (citizenship), educational appeals, and guardianship. Family Support Provider Agencies and DDS staff will help direct families to alternative resources if a family requests assistance with expenses related to guardianship.

If a Family Support provider is unsure about whether a request is an allowable expense, the family support provider should discuss with the Service Coordinator. If there continue to be questions, the Service Coordinator may confer with the Area Director/Designee, or the Regional Family Support Director. See 808 Code of Massachusetts's Regulations 1.00 et seq. (compliance, reporting and auditing for social and human services).

Utilization of family support funding to cover unapproved or disallowable expenses including those specified in these Guidelines may jeopardize the continued participation by the family in the family support program.

D. FREQUENTLY ASKED QUESTIONS (FAQs)



Q1. What is the process for authorizing the usage, distribution and monitoring of Gift Cards?

- The Department expects a limited usage of gift cards, but understands that gift cards can be very helpful in meeting more immediate and individual needs of families for assistance. When gifts cards are used, providers must have procedures in place for authorizing their distribution and monitoring the usage. This must include the keeping of a Card/Voucher Log or other system that tracks the following information: Identifier number on card; purchase date; amount; abbreviation of individual's name receiving card/voucher; date of issuance; purpose; name/title of person authorizing release of card/voucher; signature of individual who received gift card/voucher.
- As a reminder, gift cards and vouchers should be distributed in a timely way that allows them to be used before the end of the current fiscal year.
- The Department will monitor the use of gift cards to ensure that there is not excessive reliance on gift cards and/or overuse at the end of fiscal year.

Q2. What documentation is required when utilizing and paying family-hired workers via reimbursement or a cash stipend from the Family Support Center?

- If the Family Support Provider is paying the respite worker on their payroll:
 - This is not an appropriate use of flexible funding
 - This service is more appropriately provided as a Support Service through an SSQUAL contract, e.g., respite or adult companion
 - The referral and contracting for SSQUAL service is arranged by the Area Office
- If a family/individual pays the respite worker via reimbursement or cash stipend from FS Center:
 - Provide documentation of actual payment
 - The family should maintain a log/time sheet to verify services provided, dates, number of hours, and rate of pay, which is signed by respite worker and family/individual and submitted to the Family Support Center.
 - Family Support Center should share information with the families relative to labor laws and when individual workers would be considered an employee.

Q3. How do we document purchases of Goods & Equipment by the Individual/Family?

- When an Individual or Family makes a purchase, they should submit a receipt to the Family Support Center that includes item purchased, vendor, date of purchase, and amount.

Q4. How do we document purchases of Goods & Equipment by the Family Support Center? What are the requirements for the purchase of larger capital items by the Family Support Centers/Programs for individuals and families?

- When Goods and Equipment are purchased on behalf of an individual or family, the Family Support provider must obtain a receipt verifying the vendor, items purchased and date of purchase. In addition, the provider must confirm and document that the individual/family is in receipt of the item. Items purchased for a family that are in excess of a provider's capitalization level should follow standard contract rules that apply to inventory and other administrative obligations.
- For portable items such as generators: If portable, the provider would follow the process outlined above. If the generator is tied into the individual or family's electrical system, it is considered a Home Modification and the Center should follow the Home Modification Prior Approval Process.
- For home or vehicle modifications over \$1,000, the provider must follow the vehicle/home modification procedures outlined in the Family Support Guidelines.
- Please note: a provider cannot use flexible funding toward the purchase or lease of a vehicle for an individual or family.

Q5: CAN A FAMILY ACCESS FLEXIBLE FUNDING WHEN THEY ARE PROVIDING ADULT FOSTER/FAMILY CARE (AFC) IN THE FAMILY HOME?

- Flexible funding can be provided to individuals who are also receiving AFC in the family home, with some limitations to avoid duplication of services between MassHealth and DDS. Flexible funding for families providing AFC in the family home is only allowed for specific purposes and in circumstances that will address:
 - an identified need of the individual as determined by the person's planning team
 - and will be of direct benefit to the individual.

Examples of allowable goods or services may include fees for the individual to attend an adult education course, travel training, wellness or fitness groups, purchase of assistive technology or adaptive footwear. Uses that would not be allowed include: respite, payment of utility bills, and home or vehicle modifications.

There is a specific guidance that defines what other DDS services may be utilized in this circumstance, which can be found in **Section XI B** of this manual.

Q6: WHAT PROCESS SHOULD BE FOLLOWED WHEN THERE ARE QUESTIONS ABOUT THE APPROPRIATENESS OF A PROPOSED USE OF FAMILY SUPPORT FUNDING?

- If a Family Support provider is unsure about whether a request is an allowable expense, the family support provider should discuss with the Service Coordinator. If there continue to be questions, the Service Coordinator may confer with the Area Director/Designee, or the Regional Family Support Director.

E. Adult Foster/Family Care in the Family Home

For Individuals Eligible for DDS Services Informational Guidance

Overview

Many adults with intellectual disabilities who are eligible for services from the Department of Developmental Services (DDS) live at home with their families. A growing number of families are choosing to participate in the MassHealth Adult Foster Care/Family Care (AFC) program for support to help them meet the daily caregiving needs of their family member with a disability who lives with them at home. Since AFC is a MassHealth funded program DDS cannot use their DDS funding to provide duplicative services to individuals/families enrolled in the MassHealth AFC program.

This guidance is designed to provide information and clarification about the DDS in-home and family support services adults over age 18 and their families may access when they participate in the MassHealth AFC program in their own family home; which services are not available; and those services that have certain restrictions or limitations.

DDS is committed to supporting families who are caring for their family member at home and want to enable individuals and families to access services they are eligible to receive while also ensuring compliance with the MassHealth AFC requirements. It is important to stress the importance of dialogue between DDS Area Office staff, families, DDS eligible individuals, and AFC providers when making these decisions since there may be specific or unique considerations that need to be taken into account.

The Adult Foster/Family Care Program (AFC):

Adult Foster/Family Care (AFC) is a MassHealth funded program for individuals with activities of daily living needs who require daily support at home and in the community. AFC services are provided in the caregiver or individuals private home. The caregiver and the individual must live together in a private residence. The caregiver and the home setting must meet all qualifications and requirements set forth by MassHealth. AFC services include assistance with activities of daily living, instrumental activities of daily living, nursing oversight and care management. The caregiver provides meals, companionship, personal care assistance, and 24-hour supervision. Caregivers can be family members, but cannot be spouses or legally responsible relatives. An assessment is conducted by the MassHealth AFC Provider to determine the intensity of support needs of the individual. There are two levels of funding support based on the assessed needs of the individual. The caregiver receives a monthly stipend depending on the level of care needed. The MassHealth AFC Provider completes routine home visits by social workers, community health workers, and registered nurses. Individuals who qualify for the MassHealth AFC program receive up to 14 alternative caregiver days, 15 non-medical leave of absence days, and 40 medical leave of absence days per calendar year.

Relationship Between AFC Services in the Family Home and DDS Funded Services

Based on the assessed needs of the individual and as determined by the individual's service planning team/ISP:

Employment and Day Services:

Individuals can receive the full array of Employment and Day Services based on their needs

Family Support and In-Home Supports

Family Support Centers

- Individuals and families can access any of the ‘general’ services offered by the Centers including Information & Referral resources, participation in support groups, trainings and educational events as well as social and recreational opportunities, and programs.
- Families can also access Service Navigation, both short-term and extended.
 - If extended navigation is provided the referral is made by the Area Office and it is critical that the focus of this ‘case management and support service’ is different from and complements the case management services provided by the AFC Provider Agency. This would be documented in the Family Support Plan developed by the Family Support Center.

Support Services (SSQUAL) funded by DDS that individuals can access:

*Peer Support and Training

*Behavioral Supports

Support Services (SSQUAL) funded by DDS that may be allowable based on assessed needs of individual and related to goals/outcomes identified in the individual’s ISP within specific and defined service limits

- Adult Companion- for support to the individual to participate in community activities outside of the family home; {there is a maximum service limit of 14 hours/week}
- Individualized Home Supports- specific focus on skills training and development for the individual; {there is a maximum service limit of 14 hours/week}
- Speech, Physical, and Occupational Therapies after fully utilizing services available through MassHealth and/or private insurance

Flexible Funding Allocations- Are only allowed for specific purposes and in circumstances that will address:

- an identified need of the individual as determined through an assessment by the person’s planning team:
- and will be of direct benefit to the individual.

This funding needs to be administered in accordance with the *Family Support Flexible Funding Implementation Guidance* for allowable goods and services that meet the requirements stated above, with a cap of up to \$3,000/year. Examples of allowable goods or services may include purchase of adaptive equipment or communication device; fees to attend an adult education course or membership fees. Uses that would not be allowed include: respite or payment of utility bills.

Support Services and in-home/family support services funded by DDS that are not available and cannot be provided

- Respite (14 alternative caregiver days are provided through the MassHealth AFC Provider)
- Chore Services

Residential Services:

Individuals cannot access any residential services provided and funded by DDS

Medically Complex Program and Intensive Flexible Family Supports (IFFS)

Individuals and families who participate in the AFC program in the family home can receive services through the Medically Complex Program and the Intensive Flexible Family Support Services (IFFS) if there is a determined need, the family navigation services provided are different from and complement the case management services provided by the MassHealth AFC provider, and all other support services comply with the guidelines and requirements stated above.

Massachusetts Department of Developmental Services

Section: VIII - Other DDS Services/Programs

A. Support Services/Support Services Qualifying List (SSQUAL)

As part of its comprehensive array of family support options, the Department has developed a range of in-home and community support services available to children and adults living at home with their families. These services are delivered by provider agencies who have been qualified through a Request for Qualification (RFR) process administered by DDS, known as the Support Services Qualifying List (SSQUAL). Some of these services are only available to adults, some are for children, and some are for both. Examples include respite in the family home and adult companion services. A list of these support services is provided below.

Providers qualified to offer and deliver these services are responsible for recruiting, training and supervising the staff who provide these services to individuals living with their families. Standard rates have been established for these services. Individuals and families can select providers from the qualified list who are available in their geographic area to deliver the specific services they have requested and need. Some of the agencies qualified to deliver these SSQUAL services are also providers of Family Support and Autism Support Centers, or other Family Support Program services. These SSQUAL services need to be arranged and contracted for by the DDS Area Office.

SSQUAL services provide staffing support in a number of ways. Most services are designed to be provided on an individual basis, although some services may be provided to small groups of individuals or families for small group recreational or social opportunities, for example. Following are several examples of common uses of these Support Services. Respite in the Family Home is one of the SSQUAL support services often used when a family prefers to have an agency hire and directly pay a worker, or when they are unable to identify their own respite provider. Out of Home Respite is also a popular support as it allows families to get relief for an extended period of time. The use of Behavioral Supports and Consultation allows a trained clinician to work with families to address behaviors so that the family unit can stay intact and minimize the need for more costly out-of home residential services.

Many of these SSQUAL services for adults are included in the Department's Home and Community Based Waiver Programs, and for individuals participating in one of the federal Waiver programs, these services are reimbursable through the federal government.

These support services are a vital and integral part of the DDS family support system. This array of service options provide flexibility and choice for individuals and families to select which support services and service providers are best suited for their needs. These supports offer a way for individuals and families to tailor services and supports in ways that is most responsive to their needs.

Services Available To Adults Only:

1. Adult Respite Services

This includes services provided in either the home of the participant or the family home or in the home of an individual family provider/caregiver, or in a licensed respite facility to adult waiver participants who are unable to care for themselves. Services are provided on a short-term basis, including on a short-term overnight basis, where there is an absence or need for relief of those persons who normally provide care for the participant.

- **Site-Based Respite Facility – (3759)**

- **Respite In The Home Of A Care Provider – (3702)**
- **Respite In the Family Home – (3701)**
- **Respite In Recipient’s Home – Hourly (3731)**

- 2. Adult Companion Services – (3707)**
- 3. Individualized Home Supports – (3703)**
- 4. Behavioral Supports and Consultation – (3710)**
- 5. Residential\Community Peer Supports Services – (3716)**

Services Available To Both Adults and Children:

- 6. Residential\Community Family Training – (3709)**
- 7. Assistive Technology –(3283)**
- 8. Family Navigation – (3700)**

Services Available To Children:

9. Children’s Respite Services

This includes services provided in either the family home, in a licensed respite facility, or in the home of an individual family provider/care provider to children who are unable to care for themselves. Services are provided on a short-term basis, including on a short-term overnight basis, where there is an absence or need for relief of those persons who normally provide care for the participant. Respite for children may occur outside a home setting. Respite workers may also be used to accompany children and provide supervision to them for participation in community activities.

- **Site-Based Respite Facility – (3775)**
- **Respite In The Home Of A Care Provider – (3705)**
- **Respite In The Family Home – (3735)**

For detailed descriptions of Service Activity Codes and rates, please refer to
<https://www.mass.gov/lists/dds-pos-contracts-information>



B. Self-Directed Services

Many individuals and families have expressed both a desire and willingness to exercise more control of the choices and the supports that affect their lives. The Department of Developmental Services is committed to the advancement of self-determination for individuals with intellectual and developmental disabilities. The principle of self-determination is the concept of having control in one's life and to make choices based on preferences, beliefs and abilities to influence one's own future.

Through the advocacy of individuals and families, legislation was passed in Massachusetts in 2014 which resulted in the “**Real Lives Law**”. Its focus is enabling individuals to be the primary decision maker in regards to the supports they receive. With individuals as the decision makers, it is clear that there are improved opportunities for people to participate in meaningful activities, to be included in the community they live, and to have better chances to form relationships and be valued. This ability to have choice and control is vital and should be done with a person centered planning focus and ongoing communication with the Service Coordinator. Supports can be made available as needed to assist individuals in planning their own futures.

There are two self-directed service options: **Agency with Choice** and **Participant Directed Program**. Both these options provide the opportunity for more individualized and unique services. These program models also enable individuals to have more control and flexibility in creating or finding the supports and workers they need to do the things most important to them.

Agency with Choice

The **Agency with Choice Model** enables individuals and families to have an increased level of self-determination through both the choice and design of the services they select. There is a shared responsibility with the provider for the hiring and management of the employees/workers who deliver these services, which is also referred to as a *co-employment* model. Agency with Choice providers support participants to experience and build capacity for self-directing, customizing services and maximizing community opportunities and connections.

This model is beneficial for individuals who wish to have a larger role in directing their supports by having a shared responsibility in the management of the workers. The duties are split between the individual/family who serves as the *managing employer*. The agency serves as the *employer of record* and assumes the financial responsibilities of paying the workers that have been selected by individual and family; withholding, filing and paying all federal, state and local taxes and providing worker's compensation and unemployment insurance. As they are the actual employer of the worker, the AWC provider agency assures that all required background checks are completed and processed. Individuals who choose this model will be provided an individual funding allocation from the Area Office for the purchase of services to meet their needs. The individual/family will have responsibilities in hiring, budgeting, providing daily supervision and training of the workers.

In the Agency with Choice model:

- The **provider agency** is responsible for employing the staff and for other related duties of an employer and for the appropriate purchasing of all goods and services. The provider agency is responsible for managing all aspects of the budget so that the services in the contract and Individual Support Plan (ISP) are provided according to the applicable federal and state laws, DDS and other state agency regulations or other DDS requirements.

- The **individual/family** selects the employees and recommends them to the agency. They also set work hours, terms of employment and provide the daily supervision and management of the employees. They also determine when the staff is no longer needed.
- The **provider agency** and **individual/family** share in the training and evaluating of the employees.

Participant Directed Program

The Participant Directed Program (PDP) option offers the individual/family the most flexibility to arrange and customize supports based on the individual's needs and preferences. The individual can hire their own support staff, design their schedule, and make other decisions about how to use their DDS funded allocation.

In the Participant Directed model:

- The **person and/or family** self-directing make their own decisions, determine how their DDS funding is spent for services, supports and goods (within DDS guidelines), and takes responsibility for the decisions he or she makes.
- A **fiscal intermediary** (FI) serves as the agent for individuals and families and is responsible for all payments. The FI pays support workers and for other goods and services in accordance with the participant's budget. The FI provides financial monitoring and reporting and ensures compliance with all applicable federal and state laws, DDS and other state agency regulations, and with other DDS requirements.
- A **Support Broker**, typically a DDS Service Coordinator, helps the person define his or her needs and goals through a person centered planning process that leads to an individual's plan. The Support Broker helps the individual create and manage a budget within the allocated resources, and develop a network of services/supports.

Key components are as follows:

- **Individual Budget:** The Individual Budget is a mechanism that enables a participant to direct and manage the delivery of services he or she is authorized to use. By utilizing the budget an individual has control of a specific amount of funds, and the responsibility and flexibility to purchase supports, services and goods from a variety of sources (within DDS guidelines)
- **Staff Qualification:** DDS completes the process to qualify support workers hired by the individual, who must meet minimum requirements for these positions as outlined in Participant Directed Program guidance.

For more information about self-directed program options, begin by contacting the family's Service Coordinator at the Area Office. In addition, the Self-Directed Supports Manager in each Region can provide information, support and training to families, Area Office staff, and provider agencies.

Information is also available at: www.mass.gov/eohhs/gov/departments/dds/selfdirectedsupports

Additional information about self-determination and self-directed options can be found at:

- www.centerforself-determination.com
- www.ngsd.org (National Gateway to Self Determination; resources and information)

Information for this section has been excerpted from the DDS "Support Broker Procedure Manual for the Participant Directed Program".

C. DESE/DDS Program

The DESE/DDS Program is designed to provide in-home and community based therapeutic supports to children and young adults ages 6 to 22, who demonstrate a need for services to prevent a more restrictive out of home residential placement. This Program also offers an increased level of support services to families whose child returns from a residential school placement and requires assistance to remain at home. The DESE/DDS Program is administered by the Department of Developmental Services (DDS) with funding from the Department of Elementary and Secondary Education (DESE). Funding for this Program is subject to an annual legislative appropriation from the state budget.

The DESE/DDS Program requires the following to determine a student's eligibility:

- Children must be 6-17 years of age at the time of enrollment in the Program, remain DDS Eligible as a child, and must remain in an educational program provided by their local school district.
- The parent/guardian must agree to participate in an individualized assessment, and provide copies of all relevant documents such as most recent IEP and evaluations/diagnostic information. They must also share information about all other services provided to the child through school, insurance and other state funded programs.

The intent of the program is to increase family capacity to support his/her child in the home and community, as well as to provide an individualized plan of supports that promotes skill building, independence, and social integration. Families must play an active role in the program. In order to help develop these capacities the DESE/DDS Program requires that all participants receive approximately three to six hours a week of behavioral/skills training services in-home or in the community. These services may be provided by a variety of Professional Therapists and/or Skills Trainers who design/implement the In-Home objectives based on the goals identified in the Support Plan. This may include working on increasing the child's ability to carry out activities of daily living (ADL), enhancing the child's ability to communicate, and/or increasing positive behaviors through skills development.

Accessing the DESE/DDS Program:

Applicants are identified through an Open Interest process. DDS will accept Interest Forms from families at specific posted timeframes, typically every 18 months based on availability of funding. Completion of the DESE/DDS Interest Form only serves to indicate a family's interest in the Program. The submission of the Interest Form does not guarantee participation in the DESE/DDS Program, which is determined through an Assessment and Prioritization Process, based on availability of funding.

Once the period for receiving Interest Forms for the DESE/DDS Program is over, the Department will determine eligibility for the DESE/DDS Program via the process outlined below:

1. DDS will determine the number of available slots based on the current distribution of students per region, trying to ensure that each DDS region is adequately represented.
2. Area/Regional DDS staff will select families to be assessed from the Open Interest List. Once assessments are completed by Service Coordinators, families are admitted to the program based on level of need.
3. Enrollment occurs at designated intervals over the course of the year, based on the number of available spaces.
4. Once enrolled, families will select a Qualified DESE Provider agency to deliver family navigation services. The Family Navigator will help the family to develop their plan for services, monitor their budget, and help identify in-home staff and other resources.

D. Children's Autism Waiver Program

The Children's Autism Waiver Program provides one-to-one interventions to help children with autism who exhibit severe behavior, social and communication problems through a service called Expanded Habilitation, Education (intensive in-home services and supports). This service occurs in the child's home or other natural settings under the supervision of trained clinical staff and is available for up to a total of three years. The waiver also provides related support services such as community integration activities and respite. At the conclusion of the three years of intensive services, a child may access supplemental services that meet the child's needs and help with the transition out of the intensive Autism Waiver Program until the child's 9th birthday.

The Autism Waiver serves children up until their 9th birthday, with an autism spectrum disorder who meet the eligibility criteria for the Waiver Program. All waiver services require that the child continues to meet the financial and clinical eligibility requirements for the Waiver Program.

Eligibility Requirements for the Autism Waiver Program:

1. The child must have a confirmed, verified diagnosis of an Autism Spectrum Disorder, be a resident of Massachusetts, and be younger than 9 years old.
2. The child meets the level of care required for services in an Intermediate Care Facility for persons with an Intellectual Disability (ICF/ID) as assessed by DDS.
3. The child must have a legally responsible representative able to direct the services and supports of the Waiver, and the family must choose to receive services in the home and community. The child must be able to be safely served in the community.
4. The child must be found eligible for MassHealth Standard coverage, based on family income. For families who have not yet applied for MassHealth, this must be done at the time of the filing of the Waiver Program Eligibility Request Form. The family must maintain MassHealth Standard coverage throughout the child's participation in the Autism Waiver program.

Accessing the Autism Waiver Program:

Families may apply to the Children's Autism Waiver Program during specific Open Enrollment Periods. During Open Enrollment periods, families may access applications on the DDS website or through their Regional Autism Support Centers. Families who previously applied but were not selected for the AWP must re-apply at the next Open Enrollment to remain on the list of applicants. Applications are available in multiple languages on the DDS website, and translation into additional languages is available upon request.

Operation of Autism Waiver Program:

The Children's Autism Waiver Program is a statewide program whose staff includes DDS Autism Clinical Managers (located in Central Office) and Autism Support Center Support Brokers (in the Regional Autism Support Centers). When an individual is accepted into the Autism Waiver Program, the DDS Autism Clinical Manager and Autism Support Center Support Broker work with the family to develop an in-home support plan and decide on other complementary services. The Autism Support Broker assists the family in accessing services and setting up the services within the parameters of the Autism Waiver Program.

Massachusetts Department of Developmental Services

Section: IX - Role of Department of Developmental Services (DDS)

The Department of Developmental Services (DDS) is strongly committed to providing a wide array of family support services to assist families in caring for their family member with intellectual or developmental disabilities who live at home. Given the importance placed on the quality of family supports provided, the Department has a number of pivotal roles in ensuring that individuals and families receive the highest quality support across the lifespan.

Planning:

- Regional/Area Offices should continue to assess the current status of family support that is available and accessible in their respective region or areas. Planning should include identifying both the strengths and gaps in services and determining priorities for both current and future family support funding.
- DDS consultation should regularly occur with local Citizen Advisory Boards and/or family groups, comprised of family members receiving family support on the planning, implementation and evaluation of family support services.
- DDS will continue to focus its priorities on addressing the needs of unserved and underserved families across the lifespan, including outreach and supports to families who are culturally and linguistically diverse.

Policies and Procedures:

- DDS should ensure that the Family Support Program Manual and Guidelines is routinely updated and contains the most current policies and procedures in family support and is posted on the DDS website.
- The Statewide Family Support Implementation Work Group, comprised of both DDS and family support providers, will continue to review and provide input on the development and implementation of family support policies and procedures.
- DDS will continue to emphasize at all levels that family support policies and procedures be clearly communicated and consistently followed throughout the state.

Allocation of Flexible Funding Resources:

- DDS will identify individuals for family support based on need and availability of funding. The expectation is that the vast majority of families receiving family support allocations will continue to receive a consistent allocation from year to year, unless there are changes to their individual circumstances and/or DDS budget appropriations.
- The Department has developed a more consistent statewide process to allocate flexible funding to families through the Family Support Centers. **(See Section VII)** Area Offices are expected to meet with family support providers prior to the beginning of each fiscal year to determine the roster of families to receive flexible funding allocations for the next fiscal year. This list will obviously evolve over the course of the year.

Contracting:

- DDS will award family support contracts to qualified bidders through the established RFR process at the family stabilization rates set by EOHHS.
- DDS will provide consultation and monitoring of family support contracts performance through regular contract review meetings and in the re-contracting process.

Guidance and Support:

DDS will provide guidance and support to individuals and families, family support providers and DDS staff on an on-going basis to foster success in its initiatives for families.

- **For Individuals and Families:**

- DDS staff will offer opportunities throughout the year and across the state to inform individuals/families about the various support options available to them as well as to gather families' feedback about the current services they receive and any unmet needs. Service Coordinators will proactively connect families to their Family and Autism Support Centers through conversation and referral to the Centers, and identifying families who would benefit from Flexible Funding, Service Navigation and other services.
- DDS, in concert with its family support providers, will provide information verbally and in writing in the language most comfortable to the families and respectful of the family's cultural and individual values.
- DDS will continue to provide and update helpful guides and resource materials for individuals and families. This includes updating the Family Support Program Manual and Guidelines, Statewide Family Support Directory, Transition Information Fact Sheets and other family resources materials, etc. in consultation with individuals and families.

- **For Family Support Staff:**

- The Department at all levels will continue to provide guidance and support through regular collaborative meetings and trainings for family support providers. Regional Family Support Directors will continue to convene regular meetings with Family Support Providers in each Region.
- The Department will provide regular statewide opportunities for the IFFS, Medically Complex and Family Leadership program staff to discuss relevant issues, challenges and future direction.

- **For DDS Staff:**

- DDS will provide training opportunities in all regions and on a statewide basis to discuss family support policies and procedures, as well as new family initiatives.
- DDS will encourage and support local family support initiatives and innovation projects that address family support goals and principles including opportunities for social inclusion and community engagement.

Quality Assurance and Program Monitoring:

- The Department will continue to collect family support data, provide analysis and share statewide summary reports internally with Regional and Area Offices as well as with family support providers, the Statewide Family Support Council and other family advocacy groups. **(See Section XII, Family Support Data Reporting)**
- As a part of the contract review process, DDS Regional/Area Offices will implement the Family Support Center Quality Review Process consistently with all of its family support and cultural/linguistic family support centers across the state.
- The Department will work with DDS Area Offices and Family Support Provider Agencies to implement consistent administrative practices for authorizing, monitoring, and reporting of flexible funding allocations to ensure accountability in the management of these state funds.
- The Department will work to identify and spotlight best practices in family support and share them in a variety of venues and formats.
- DDS will continue to offer a series of statewide trainings to enhance the delivery of high quality family supports, including its annual Statewide Family Support Conference.

Massachusetts Department of Developmental Services

Section: X - Administrative Responsibilities of Family Support Provider Agencies

A. Program Administration

This Section specifically describes the Administrative Responsibilities for Family Support Provider Agencies that are delivering services procured by DDS in the Request for Response (RFR) **FSS-10 for Family Services-Designated Programs**. These services include Family Support Centers; Cultural/Linguistic-Specific Family Support Centers; Autism Support Centers; Intensive Flexible Family Support Services (IFFS); Medically Complex Programs; Planned Facility-Based Program for Children; and Family Leadership Programs.

Other In-Home and Community Supports, often referred to as “SSQUAL Services” are discussed in Section: VIII (A) of this Manual.

1. Contracting

- **Providers need to follow these steps in the Contracting Process;**
- Family Support Providers must be selected and/or qualified through the RFR process for the service(s) they intend to provide. RFR’s are listed in COMM-BUYS.
- Providers work with Area Office or (Regional Office) to coordinate the implementation of the specific service(s), honoring the framework of the RFR.
- Provider submits a draft contract to the Area Office and Regional Contracts Office. (Required forms are listed on the DDS website under Contracting & Procurement).
- Once approved, final contracts are submitted to Regional Contract Office and loaded in EIM Billing website. Providers can begin to initiate services.
- When necessary, providers work with Area Offices and/or Regional Offices to process amendments to their contracts.

2. Contract Reviews

- Regular family support contract meetings between the Area Office (or the Regional Office if it is a regional contract) will be held on a quarterly basis, unless otherwise specified. This meeting can review contract spending as well as other program outcomes and individual/family issues and needs, including decisions regarding individual flexible funding allocations.

3. Billing

Providers will use the EIM website to bill monthly for services rendered. Training is available for providers to learn about the EIM system.

B. Programmatic Requirements and Expectations

1. Infrastructure:

- Each Family Support provider shall create an infrastructure that supports the staffing and ancillary supports necessary to offer the array of family support services that meets their contractual requirements and responsibilities under RFR FSS-10.
- Each Family Support provider shall identify a staff member to act as its family support coordinator to provide oversight and direction for the programs.
- Family Support providers are expected to provide sound administration of the program:

- Fiscal management and invoice preparation
- Submission of required DDS reports in a timely and complete manner
- Clerical and other necessary support

2. Administration of Flexible Funding Allocations

Family Support providers must adhere to the principles, guidelines and procedures found in **Section VII- Individual Flexible Funding Allocations** of this Family Support Program Manual and Guidelines.

3. Staffing Requirements

Staff hired by Family Support providers for agency-delivered services under RFR FSS-10 typically fall into three categories:

- **Family Navigators/Coordinators** in Family Support Centers, Cultural/Linguistic-Specific Family Support Center, Autism Support Centers, IFFS, Medically Complex Programs, etc.
- **Program Staff** working directly with individuals in Family Support Center programs. This could include afterschool programs, social/recreational programs, camps, and other Center/Program activities. **Note:** this does not include staff providing SSQUAL services, or paid directly by families.

a. Qualifications of Agency- Paid Staff

Individuals who are hired by and on the Family Support provider payroll to provide support services shall meet the following requirements.

➤ Age

The minimum age for a staff person employed by a Family Support provider who is working directly with individuals and their families is 18 years old. An exception can be made for someone under 18 years old if the individual is working in a center-based program with adult supervision present whenever program participants are in attendance.

➤ Qualifications

Applicants must possess appropriate qualifications to serve as family support staff as evidenced by relevant education and/or experience, interviews, personal and/or professional references and a Criminal Offense Records Inquiry (CORI) check and National Criminal Background Check/Finger Printing.

➤ Communication

Staff members shall have the ability to communicate effectively in the preferred language and communication style of the individual to whom they provide services and his or her family.

4. Staff Training

a. General Requirements:

- Each Family Support Provider Agency is responsible for orienting all employees to the Agency's philosophy, goals, organizational structure, services, benefits, policies and procedures, and to the specific responsibilities of the employee's job.
- Each Family Support Provider Agencies shall provide or arrange relevant training for its staff. Agencies are required to maintain written documentation of training it provides including schedule and attendance records.
- Agencies shall have written policies on file for waiving training requirements for any family support staff who have completed equivalent training, or who meet the required level of training demonstrated by equivalent qualifications or experience.

- b. Core Training Requirements:** Sufficient training and mentoring of each employee should be provided to ensure that they are competent to provide services to individuals and families. This requirement may be met by a demonstration by the employee of knowledge and competence acquired through comparable training and/or experience.

CORE TRAINING FOR NAVIGATORS AND COORDINATORS, to be completed within the first 90 days of employment:	
Topic	Content
Values and Principles of Family Support	<ul style="list-style-type: none"> • Guiding Principles of Family Support • Historical Perspectives and Family Leadership • Overview of Family Support Programs • Community Membership and Connections • Cultural/Linguistic Diversity • Person-Centered Philosophy • Self Determination
Emergency Procedures	<ul style="list-style-type: none"> • Medical Emergency Procedures • Lost Consumer Procedures • Fire Drill Procedures
Health and Safety*	<ul style="list-style-type: none"> • Basic First Aid/CPR, including Seizure Training (basic information) • Safety in Home Visits and Outings • Vehicle Safety • Universal Precautions
Human Rights	<ul style="list-style-type: none"> • Human Rights* • Mandated Reporting of Abuse and Neglect* • Individual Rights and Responsibilities? • Social and Sexual Development
Program Procedures	<ul style="list-style-type: none"> • Family Support Guidelines • Family Support Forms: Data Collection • Consumer Record/Privacy and Confidentiality • Incident Reporting
Working with Individuals and Families	<ul style="list-style-type: none"> • Getting to Know an Individual and/or Family • Managing Boundaries • Confidentiality • Overview of Intellectual and Developmental Disabilities
Systems Overview	<ul style="list-style-type: none"> • DDS 101 • Overview of Individual Service Plan Process • Overview of Individual Educational Plan Process • Introduction to Positive Behavioral Supports
Job Responsibilities	<ul style="list-style-type: none"> • Reviewed Job Specific Job Description • Job Specific In-Service Requirements Reviewed • Expectations for Continued Professional Development
Agency Policies and Procedures	
<i>*Denotes training required on an annual basis</i>	

PROGRAM STAFF CORE TRAINING:

Given the part-time status of most Program Staff, the Core training requirements to be accomplished in the first 90 days of employment have been modified. There can be adjustments and flexibility in training formats and materials to accommodate people who only work a few hours a week, or intermittently (such as for week-long vacation camps).

<i>Topic</i>	<i>Content</i>
Values and Principles of Family Support	<ul style="list-style-type: none"> • Guiding Principles of Family Support • Community Membership and Connections
Emergency Procedures	<ul style="list-style-type: none"> • Medical Emergency Procedures • Lost Consumer Procedures • Fire Drill Procedures
Health and Safety*	<ul style="list-style-type: none"> • Basic First Aid/CPR, including Seizure Training (basic information) • Safety in Home Visits and Outings • Vehicle Safety • Universal Precautions • Blood Borne Pathogens
Human Rights	<ul style="list-style-type: none"> • Human Rights* • Mandated Reporting of Abuse and Neglect* • Incident Reporting
Working with Individuals and Families	<ul style="list-style-type: none"> • Getting to Know an Individual and/or Family • Managing Boundaries • Confidentiality
Job Responsibilities	<ul style="list-style-type: none"> • Reviewed Job Specific Job Description
* Denotes training required on an annual basis	

c. In-Service Training

1. Family support and agency respite staff shall receive ongoing training necessary to provide quality support to the individuals and families they serve throughout the lifespan of the individuals and families.
2. Documentation of attendance at trainings and/or training waivers for those showing competence in a given skill area shall be kept on file at the Family Support provider.

C. Data and/or Reporting**1. Family Support Provider Agencies will submit the following to DDS**

- a. Family Support Plans, annually, and any updates or revisions;
- b. Roster of individual/family allocations and updates;
- c. Flexible Funding Expenditure Plans and modifications (as outlined in Section VII B3);
- d. Required billing, flexible funding invoice documentation form, and service delivery reports (monthly);
- e. Summary of the annual evaluation of consumer/family satisfaction, including a plan to respond to identified concerns and recommendations;

2. Annual Reports

Family Support and Cultural/Linguistic-Specific Family Support Centers and Autism Support Centers are required to submit the Center Semi-Annual Data Report twice a year. Other family support programs, including the Intensive Flexible Family Supports (IFFS), Medically Complex Programs, and Family Leadership Programs, will submit Annual Reports (See Section XII).

D. Record-Keeping

The Family Support Provider Agency shall maintain a written record for each individual and family receiving the following family support services; Extended or Short-term Navigation and/or Flexible Funding Allocations. Each record shall include at a minimum:

- a. Documentation of DDS eligibility and referral for family support services;
- b. Name, address, and telephone number of people to contact in case of emergency (in a readily accessible place);
- c. A record of special medical/health needs of the individual, if any;
- d. A copy of the Family Support Plan, if required;
- e. Records of critical incidents;

E. Complaint Resolution Process

- Each Family Support Provider Agency shall have a written complaint resolution process available to individuals and families who raise concerns/issues (i.e. Flexible Funding Allocations, Quality of Service Issues, etc.). Determinations made pursuant to such process are subject to review by DDS.
- Each Family Support Provider Agency shall do the following:
 - Inform families regarding the complaint resolution process.
 - Provide families with a copy of the process, upon request.
 - Advise families and individuals of their right to have decisions reviewed by the DDS Area or Regional Office staff and provide relevant contact information.
 - With regard to decisions concerning eligibility for DDS supports, individual's appeal rights are set forth in DDS regulations.

F. Mandated Reporting

➤ For Children:

1. The Department of Children and Families (DCF)

To Make a Report on person less than 18 years of age contact:

Hotline 24/7 call 800-792-5200

Local DCF office which can be found at www.mass.gov/dcf (9:00 to 5:00 M-F)

Massachusetts law requires mandated reporters to immediately make an oral report to DCF when, in their professional capacity, they have reasonable cause to believe that a child under the age of 18 years is suffering from abuse and/or neglect. All Family Support Provider Agencies are Mandated Reporters. Mandated reporting must be a part of the staff training provided by the FSPA.

Any physical or emotional injury resulting from abuse should be reported; any indication of neglect, including malnutrition; any instance in which a child is determined to be physically dependent upon an addictive drug at birth; any suspicion of child sexual exploitation or human trafficking; or death as a result of abuse and/or neglect.

All mandated reporters are required by law to mail, fax or mail a written report using the template provided. **Document:** [Report of Child\(ren\) Alleged to be Suffering from Serious Physical or Emotional Injury by Abuse or Neglect](#)

2. Office of Child Advocate (OCA)

The mission of the OCA is to ensure all children in the Commonwealth receive appropriate, timely and quality services with full respect for their human rights. Through collaboration with public and private stakeholders, the OCA examines services to children to identify gaps and trends, and makes recommendations to improve the quality of those services. The OCA also serves as a resource for families who are receiving, or are eligible to receive, services from the Commonwealth. Anyone with concerns about a child or youth receiving services from a state agency can contact the OCA.

There is another important reporting requirement that Family Support Centers and Autism Support Centers, Medically Complex Programs, IFFS, DESE/DDS Program, Planned Respite for Children and the Autism Waiver Program need to be aware of when it comes to children they serve. All of these DDS funded programs have a requirement to immediately report to DDS Service Coordinators “critical incidents” involving children served by DDS. Critical incidents are defined as ones where a child has been seriously injured or the subject of abuse or the death of a child. DDS is then required to report these incidents to EOHHS and to the Office of the Child Advocate (OCA) in a timely way. **The DDS Service Coordinator is responsible to complete the required form and forward it to their respective Area Director.**

- **For Adults:**
Disabled Persons Protection Commission (DPPC) (24 hours / 7 days a week)
Ages 18 to 59
1-800-426-9009 or 1-888-822-0350 TTY

Instances of suspected abuse or neglect must be reported immediately to the DPPC's 24-hour Hotline at 1-800-426-9009 or 1-888-822-0350 TTY. A written report of abuse or neglect must follow within 48 hours of the verbal report to the hotline. Mandated Reporters should not rely on others, such as supervisors or administrators, to file reports for them.

Deaths of persons with disabilities must be reported to DPPC's 24-hour Hotline at 1-800-426-9009 or 1-888-822-0350 TTY. A written report must follow within 48 hours of the verbal report to the hotline. Deaths must be reported regardless of whether abuse or neglect is suspected.

Abuse or neglect committed against persons with disabilities might also be a crime. Call your local police immediately if you think a crime, such as an assault and battery, sexual assault, rape or larceny has been committed. In an emergency, contact your local police department by dialing 911.

- **For Elders:**
Executive Office of Elder Affairs (24 hours / 7 days a week)
Ages 60 and over
1-800-922-2275

The Executive Office of Elder Affairs has a centralized, 24/7 Hotline for receiving and screening reports of Elder Abuse in Massachusetts. DDS and its providers continue to report allegations of suspected abuse involving elders **through the DPPC (1-800-426-9009).** DPPC will ensure that the report is forwarded to Elder Affairs. The report to DPPC will fulfill their obligation as mandated reporters. For reporting suspected abuse or neglect of elders who are not DDS individuals (Ages 60 and over), please contact the EOEA Hotline.

Massachusetts Department of Developmental Services

Section: XI - Relationships To Other State Agencies

A. Overview

As individuals with disabilities and their families travel on their life journey, their experiences at various life stages shape the positive direction of their lives. Most families interact with multiple state agencies over the course of their lives. Family support navigators and DDS service coordinators continue to play pivotal roles during these different life stages by assisting individuals and families in looking at their choices and options. They also play an instrumental role in identifying resources that can be helpful for individuals and families to consider when addressing key issues and needs at these critical times. This requires that staff have both the knowledge of the programs and services provided by the other state agencies as well as having relationships over time with other state agency contacts. These relationships with other state agencies help staff guide families in creating more opportunities for self-determination, building social capital, and establishing economic security and community membership for both themselves and their children.

The Department of Developmental Services (DDS) and its Family Support Providers have collaborated over the years with other state agencies in order to address the multiple needs of both children and adults with various disabilities and their families. DDS intersects with the other State Agencies at different life stages based on the age of the individual and whether they meet certain eligible criteria for other agency programs or DDS. This interagency coordination and partnerships enable the state to provide more cost effective and responsive services to its consumers throughout the Commonwealth by filling some of the gaps that may result in emergencies and the provision of more costly alternatives.

Services provided by other state agencies generally complement those provided by DDS, but there are some circumstances when services from other agencies could duplicate those provided or funded by DDS. In this circumstance, coordination of services is an important role for family support providers and Service Coordinators. These circumstances are noted in this section.

Across the lifespan, families will often utilize MassHealth, either as a primary or secondary health insurance provider. MassHealth's CommonHealth program provides supplemental insurance for individuals with disabilities who have private insurance as their primary. Individuals who access CommonHealth may also qualify for the MassHealth Premium Assistance Program, which helps working individuals and families pay for employer-sponsored health insurance coverage.

Section B. describes the intersecting roles of DDS and its family support programs and their various collaborations with schools and other state agencies at the different life stages of the individual and family.



Interagency Collaboration

B. Intersection with Other State Agencies at Different Life Stages

1. Pre-Natal/Infancy

Children from birth to five years of age are eligible for DDS services if they have a substantial developmental delay. Families of very young children may access the DDS Family Support and Autism Support Centers at any time. These Centers can provide assistance in submitting an application for DDS eligibility and provide assistance and support throughout the intake process as requested by families. However, children from birth to three years old with developmental disabilities are entitled to Early Intervention (EI) services through the **Department of Public Health** (Public Law 99-457), including access to the DPH Regional Consultation Programs, and these should be their primary source for support. Family Support Centers and Autism Support Centers should establish relationships with the EI programs in their areas. Some Centers are providing programs and activities that are targeted specifically for very young children with disabilities as well as networking opportunities for families as they transition out of Early Intervention Programs.

2. Early Childhood

As a child enters early childhood, often their disability becomes more clearly defined, which may prompt referrals to other state agencies, including: **Massachusetts Commission for the Blind (MCB)**; **Department of Mental Health (DMH)**; **Department of Public Health (DPH)**; **Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)**; **MassHealth**; **Department of Children and Families (DCF)**, and **Department of Elementary and Secondary Education (DESE)**.

Family Support Navigators and DDS Service Coordinators should explore whether the children and youth they support are eligible for three key programs/resources offered by MassHealth; EPSDT, the Children's Behavioral Health Initiative (CBHI) and ABA Services;

- Children, teens, and young adults under 21 who are eligible for MassHealth Standard are also eligible for **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services**. This includes all medically necessary services covered under the law.
- **MassHealth Services for Children and Youth** include home and community-based behavioral health services available to MassHealth enrolled children and youth under the age of 21. These **CBHI** services include Intensive Care Coordination, In-Home Therapy, Family Support and Training, Therapeutic Mentoring Services, In Home Behavioral Health Services, and Mobile Crisis Intervention, as well as other MassHealth services for children and youth.
- MassHealth is able to cover medically necessary **ABA services** for children with autism under age 21.

In addition to its other family support programs, the **Department of Developmental Services (DDS)** operates a statewide Children's Autism Waiver Program (AWP) which helps children with autism (birth through eight years old) who exhibit severe behavioral, social and communication problems. The AWP provides intensive in-home services and

supports under the supervision of trained clinical staff. Families may apply to the AWP during specific Open Enrollment Periods which the DDS circulates broadly across the state.

3. School Age

Once a child with a disability enters school, their primary supports are provided under an educational entitlement, the Individuals with Disabilities Education Act (IDEA) at the federal level, and Chapter 766 at the state level, until the age of 22 or when the student graduates with a diploma. Although not the primary agency of support, DDS Family Support Programs can be extremely helpful during this critical time in a family's life, as they can have a tremendous impact not only on the child's school life but also on the life of the family.

Family Support programs are able to help families navigate special education by offering IEP trainings and clinics for individual consultation, and by accompanying families to IEP Team meetings. They may also support families in finding educational advocates when needed, including bilingual advocates for families who speak other languages. DDS Area Offices often reach out to school districts in their catchment area to share information about DDS eligibility, services and the transition process via trainings, resource fairs, etc.

Because DDS supports complement the educational services that the child and family receive in their home and community, the local school district is responsible for conducting assessments that should provide information needed to determine whether the child might be eligible for DDS services. A child is entitled to the initial evaluation free of cost from the school district. DDS does **NOT** provide educational funding or cost share mandated entitled services such as transportation, extended day services, or residential placements.

Specifically, DDS does NOT provide funding for out of home placements such as residential schools, community group homes, and foster care, etc. for individuals less than 22 years of age.

When multiple agencies are involved with a child's situation, the DDS Service Coordinator will work collaboratively with other key agency staff to ensure the coordinated delivery of services. The DESE/DDS Program represents a successful example of a statewide partnership between the **Department of Elementary and Secondary Education (DESE)** and the **Department of Developmental Services**, to provide in-home and community based therapeutic supports to students ages 6 to 22 to prevent a more restrictive out of home placement or return a student home from a residential placement.

The Autism Omnibus Act requires MassHealth to cover medically necessary ABA services for children with autism under age 21. Many school age children also benefit from other MassHealth services such as: community-based behavioral health services (CBHI), Personal Care Assistance (PCA), and access to medical equipment, absorbent products for incontinence, assistive technology for communication, therapeutic services such as OT, PT, speech, etc.

Both the **Department of Developmental Services (DDS)** and the **Department of Children and Families (DCF)** offer family supports via their respective family support centers across the state. DDS has Family Support Centers in all its areas across the state while DCF has Family Resource Centers in each County of the state. The two agencies

continue to strengthen their partnerships through their centers by sharing their expertise and knowledge of community resources for the mutual individuals/families they serve.

4. Transition

The transition years from age 14 to 22 present both opportunities and difficult decisions for students and their families as they begin to develop their vision for life after their school years. During this age span, school districts must provide appropriate transition services to meet the needs of students with disabilities. This includes exploring various services and options available from other state agencies and community resources.

DDS and school districts have developed and strengthened partnerships with the **Massachusetts Rehabilitation Commission (MRC)** and the **Massachusetts Commission for the Blind (MCB)** in supporting transition-age youth with disabilities. Both agencies are able to provide services such as job exploration, workplace readiness, work-based learning experiences, self-advocacy and support post-secondary education programs. School districts are also able to develop relationships with local colleges and universities, including programs such as the **Massachusetts Inclusive Concurrent Enrollment Initiative (MAICEI)**. MAICEI provides dual enrollment opportunities to high school students, age 18-21, that have intellectual and developmental disabilities in an inclusive college experience.

DDS Service Coordinators and Family Support Program staff play an important role in supporting families with transition-age youth. This can include: providing training and individual support to the student and their family in creating a vision for life after school, accompanying families to IEP meetings, providing or referring the student to skill-building and pre-vocational opportunities, and helping to connect families to other agencies and resources in their community.

5. Adulthood

Given the diverse needs of adults with intellectual and developmental disabilities, they may qualify for multiple adult state agency services. Other state agencies that may provide support resources include: **Massachusetts Rehabilitation Commission (MRC)**; **MassHealth**; **Executive Office of Elder Affairs (EOEA)**; **Department of Mental Health (DMH)**; **Department of Transitional Assistance (DTA)**; **Department of Public Health (DPH)**; **Massachusetts Commission for the Blind (MCB)**; and **Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)**, etc. The DDS service coordinator and family support providers work collaboratively with other key agency staff to respond to the needs of each individual and the family.

MassHealth provides long-term services and supports in a home or community setting for qualifying individuals. These services can include home health care, personal care, day habilitation, respite, physical and occupational therapy, Adult Foster/Family Care, home modification, assistive technology and other supportive medical services.

6. Aging

As individuals with disabilities and their caregivers age, they will need access to additional resources to live well and thrive in their communities. The Department's family support programs are able to reach out to these older caregivers by taking a person-centered approach with the individual and family to listen and identify what their specific needs are

and the specialized supports that might be of interest to them, such as in-home support, a support group, transportation, social events, financial support, etc.

The Executive Office of Elder Affairs (EOEA) has as its mission to promote the independence, empowerment, and well-being of older adults, individuals with disabilities and their caregivers. The EOEA and the Aging Network of **Councils on Aging (COAs), Aging Services Access Points (ASAPs), Area Agencies on Aging (AAAs) and Aging and Disability Resource Consortia (ADRCs)** have an extensive array of programs and services to offer based on an assessment of individual/family needs. DDS Service Coordinators and family navigators are able to assist individuals and families in exploring these potential resources and their appropriateness for their particular situation.

The Office of Long Term Services and Supports (OLTSS) provides MassHealth members access to a continuum of service options to support independence, choice, wellbeing and dignity in every community. These include a range of health and health-related services through both its PACE: Program of All-Inclusive Care for the Elderly and Senior Care Options Program (SCO) with a goal of maintaining seniors safely in their communities.

Additionally, the MA Legislature has established **The Commission on the Status of Grandparents Raising Grandchildren** which is a **permanent commission** to serve as a "resource to the commonwealth on issues affecting grandparents". Some DDS family support centers have organized grandparent support groups that respond to the unique needs of grandparents raising grandchildren with intellectual and developmental disabilities and are participating in activities offered by the statewide commission.



*I can't change the direction
of the wind, but I can adjust
my sails to always reach
my destination.*

Jimmy Dean

The Garcia Family



The Garcia family is an excellent example of supporting the whole family with a family member with a disability throughout the lifespan via collaboration with other agencies and programs. Dominga and her husband, Nicholas, lovingly cared for their son, Nick (who is now 55 years of age) as a team until Nick's father passed away a few years ago. As Dominga shared "The care didn't change. His father and I have always done everything for him. After his father passed, I had to help him just the same even with my health issues, he comes first". Noemi, Dominga's youngest daughter continues to be a huge support for her mom and brother. As an older caregiver Dominga (now 76 years old) proudly shares "Noemi does everything for me, for us! She's like another mother to Nick. There is no one like my daughter. I know she will take care of Nick when I am gone."

For 30 years, the family has been connected with Fidelity House Human Services, a Family Support Provider Agency in the Northeast Region. The family has been involved in the Fidelity House Latino Medical Program and attended their support groups. The program also helped mom and Nick to get to appointments. Dominga and her daughter now participate in the agency's Elder Caregiver Program, which was able to support the family in obtaining help with Meals on Wheels, one hour of homemaking, and two hours of companion services through the Elder Services of the Merrimack Valley. They also were able to set up PCAs for Nick and assist Dominga in obtaining medical equipment for herself.

*"The journey of a thousand miles begins with one step."
Lao Tzu*

Massachusetts Department of Developmental Services

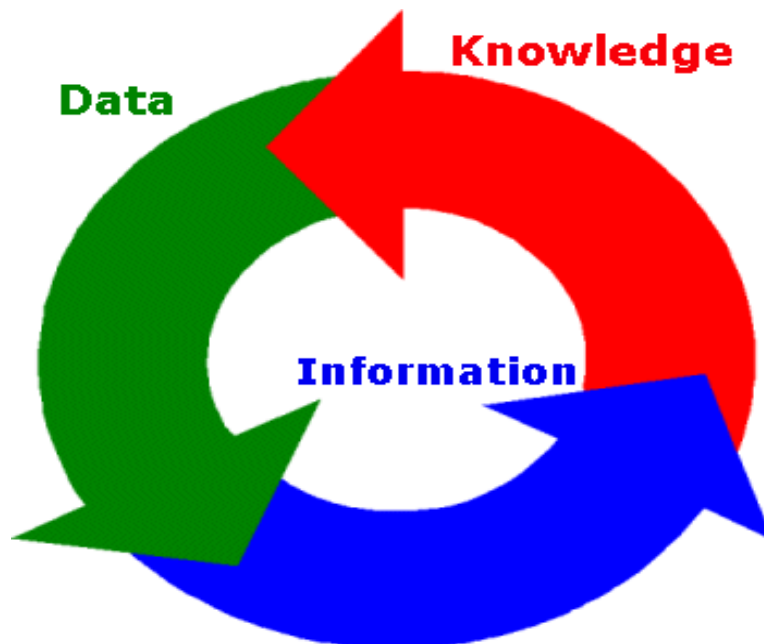
Section: XII - Family Support Data Reporting Process

A. Family Support Data Collection

Data collection and reporting is an important DDS contractual requirement that is intended to gather information about the quantity and quality of the Department's family support system across the Commonwealth. The information and data that is collected through a variety of approaches is designed to "tell the story" about the effectiveness, impact and benefit of the family support services.

Specific Purposes Include:

- To provide data and information on the number of individuals/families who are receiving different family support services offered by the Department.
- To capture information about new initiatives, special partnerships and community affiliations that the family support programs have developed.
- To use the data and knowledge to help identify greatest areas of need and interest among families, and help to identify "gaps in services".
- To support budget planning and advocacy to address priority needs.



On the next page is the specific Family Support Data Reporting Process for each of the Family Support Services.

Family Support Data Reporting Process

Family Support Centers Semi-Annual Reports

Who Completes?	All Family Support and Cultural/Linguistic Family Support Centers
When is the report due?	Semi-Annually: after first six months and end of fiscal year
Who receives the report?	Area Director(AD) and Regional Family Support Director(RFSD)
Who forwards it on and to whom?	RFSD completes Regional Report and sends to Statewide FS Director
Is there a Statewide report generated?	Yes, Statewide Family Support Center Report

Intensive Flexible Family Support Programs Annual Report

Who Completes?	All IFFS Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	AD and RFSD both receive Area IFFS Reports; RFSD receives Regional IFFS Reports directly
Who forwards it on and to whom?	RFSD reviews Annual IFFS Reports and completes summary data sheet on all the IFFS programs in region; forwards them to Statewide Director of Family Support
Is there a Statewide report generated?	Yes, Statewide IFFS Summary

Medically Complex Programs Annual Report

Who Completes?	All Medically Complex Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	Regional Family Support Director(RFSD)
Who forwards it on and to whom?	RFSD reviews Annual Report(s) and forwards to Statewide Director of Family Support
Is there a Statewide report generated?	Yes, Statewide Medically Complex Programs Summary

Family Leadership Programs Annual Report

Who Completes?	All Family Leadership Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	Regional Family Support Director (RFSD)
Who forwards it on and to whom?	RFSD reviews Annual Report(s) and forwards to Statewide Director of Family Support
Is there a Statewide report generated?	Not at this time. DDS holds Statewide meeting of all Family Leadership Programs to review the year and set new goals.

Autism Support Centers Semi-Annual Report

Who Completes?	All Autism Support Centers
When is the report due?	Semi-Annually: after first six months and end of fiscal year
Who receives the report?	Assistant Commissioner of Policy, Planning and Children's Services and Regional Family Support Directors and Regional Autism Coordinators receive all reports.
Who forwards it on and to whom?	Regional Family Support Directors should forward reports for centers in their respective regions to Statewide Director of Family Support.
Is there a Statewide report generated?	Not at this time.

NOTE: The actual formats for these Annual Data Reports can be found in Section: XVI – Appendices/Attachments.

Massachusetts Department of Developmental Services

Section: XIII - Quality Assurance

A. Family Input and Satisfaction With Family Support Programs

There should be regular opportunities for family input and feedback that are extended to families who receive family support services. At least annually individuals and families served by the Family Support provider shall have a formal opportunity to voice their opinions regarding family support services, identify unmet needs, and suggest new ideas and approaches for supporting families through a satisfaction survey and/or family forums.

Family Support providers are expected to share the results of the annual satisfaction survey or feedback from families in a written summary to families and the Area or Regional Office. This summary will document the number of families who participated in the individual and family feedback process and include a plan of action, jointly developed with families, that responds to concerns and identified needs.

If a family has a concern or an issue with the adequacy and/or the quality of a family support program, the family should initially approach the family support provider. Each Family Support provider should have a written Complaint Resolution Process which outlines the steps in their process. **See Section X, (E).** If still dissatisfied with the response, the family should contact their Area Office. After exhausting these steps, the Family Support Director in each region is a resource for families to consult for questions or issues that are unresolved or require more clarification.

The Department of Developmental Services (DDS) has the option to do a statewide family support satisfaction survey or family forums to provide another vehicle for families to voice their opinions about the quality and adequacy of the family supports they receive from the Department and its family support agencies.

The Family Support providers may also want to consider the creation of a Family Advisory Board or Council, consisting of a majority of family members. This Board would advise the family support provider regarding the planning, implementation and evaluation of the agency family support services and supports. All families would be notified of the Family Support Advisory Board and how to contact them for information and/or support.



B. Data Reports

Family Support and Cultural/Linguistic-Specific Family Support Centers and Autism Support Centers are required to submit a Semi-Annual Data Report twice a year. Other family support programs including the Intensive Flexible Family Supports (IFFS), Medically Complex Programs, Family Leadership Programs will submit Annual Reports. These Annual Reports not only give quantitative data on the number of individuals/families that are receiving different services offered by family support programs but also provide valuable information on the effectiveness, impact and benefit of each type of program service and/or special initiatives and partnerships. (See Section XII for Data Reports)

Area and Regional Offices should utilize the data and other information found in the Annual Reports to inform the Family Support Contract Review meetings with family support providers as an opportunity to recognize and/or enhance the quality of supports. The discussions and plans that emanate from these contract review meetings will provide important and constructive information for the Family Support Center Quality Reviews for family support centers as well as other family support programs.

C. Family Support Contract/Program Review Meetings

Regular Family Support Contract/Program Review Meetings between the Area Office (or the Regional Office if it is a regional contract) with the family support provider agency will be held on a quarterly basis, unless otherwise specified. These meetings cover a variety of topical areas but generally include a review of contract spending as well as other program outcomes and a discussion of individual/family issues and needs.

If the Department, family support provider or both feel the need to clarify new program initiatives and/or quality enhancement issues, the Quality Review Summary could be used to document any follow up plans or actions, including specific performance goals and objectives.

D. Family Support Center Quality Review

The Family Support Center Quality Review is a dynamic process which ensures that family support centers provide an array of supports and services that are responsive to the changing needs of individuals with disabilities and their families across the lifespan. This Review is intended to engage family support agencies and DDS in a constructive dialogue about the goals and outcomes set forth in the Request for Response #FSS-10 for family support centers. It is designed as a positive quality enhancement process, and is expected to be conducted on an annual basis.

Family Support Centers, like all other family support programs, are expected to operate with the following guiding principles:

- Individuals with disabilities and their families are recognized as primary decision- makers about their lives and supports.
- Family support focuses on the whole family and recognizes what benefits the whole family also benefits the person with a disability.
- Family support requires flexible options that are responsive to families' unique needs, strengths, and cultural values.

- Families are afforded opportunities for increasing control in the planning, implementation, management, and evaluation of satisfaction of family support services.
- Families are encouraged and supported to develop their natural capacities for innovation, initiative, and leadership.
- Family support operates in ways that respect individuals with disabilities and their families as valued members of their communities.
- Family support should be equitably and fairly available throughout the state.
- Family support is pro-active and encourages family independence and capacity-building.
- Family support builds on existing natural and community supports, and maximizes the use of generic resources.

In addition to the above principles, there are other principles and expectations specific to the Family Support Centers which are outlined in this Quality Review Tool.

Implementation Process:

The Family Support Center Quality Review will enable Family Support Centers and DDS staff to work collaboratively to identify program strengths as well as focus areas for future development. This Quality Review process should integrate and build upon the information and data generated through the Semi-Annual Data Reports for Family Support and Cultural/Linguistic Centers. Although this Tool provides a comprehensive portrait of a quality Family Support Center, it is expected that Area Offices and providers will tailor their discussion and review based on the size of the Center including a review of its current # of FTEs and the adequacy of that number of staff to support the unique needs of the families and communities served by each Center.

These are the steps in this review process:

- Before the beginning of this process, both Area Office and FS Center staff will have read and reviewed the tool to have a general familiarity with all the general principles and center services and program requirements. There should be a discussion about the approach for completing this process and whether any preparation would be helpful. It is not required that people go through every question in the tool each year. The discussion should build from year to year based on successful outcomes and new issues that surface. It would also be important to invite the Regional Family Support Director to participate in the process.
- It is expected that the review process will be completed at the beginning of the fiscal year, but no later than the end of September, and the mid-year review will occur approximately six to seven months after that, in February/March.
- At the initial DDS/FSC program meeting, the Area Office and the FS Center agency will reflect on the past year using the guiding and probative questions in the quality review tool, as well as utilize and integrate the data and information found in the Semi-Annual Data Reports/Year End Report and previous program monitoring discussions around successes, challenges and/or new initiatives.
- Focus areas for development and improvement and corresponding action steps will be mutually agreed upon for the coming year and documented on the Family Support Center Quality Review Summary.

- At the mid-year, these focus areas and action steps will be revisited to review progress and accomplishments. If necessary, changes should be made.
- The Family Support Center Quality Review should be viewed as a positive quality enhancement process from year to year. At the end of the fiscal year, the focus areas and action steps will receive a final review in preparation for setting next year's goals.
- The final Family Support Center Quality Review, including the Family Support Center Quality Review Summary, needs to be shared not only with the Family Support Provider and the Area Office but also the Regional Family Support Director. In their regional role, the Regional Family Support Directors can use this information in Regional and statewide family support planning, budget advocacy and quality assurance efforts. The Family Support Directors will also be able to identify and/or locate "Best Practices in Family Support" across the region or statewide that may benefit a particular program or situation.



- The Family Support Center Quality Review embodies a "continuous improvement" process. It starts with a strong commitment to shared values and goals for supporting individuals and families with quality support across the lifespan. The Quality Review lays out the Vision and Mission for Centers, including specific program expectations and deliverables. DDS and its Family Support Providers implement a collaborative and ongoing process to analyze what's working and what's not. This includes mapping out specific strategies to improve performance and quality outcomes for individuals and families over time.

*"If we do not change our direction, we are likely to end up where we are headed."
Ancient Chinese Proverb*

Family Support Center Quality Review -- (SAMPLE)

Updated: 6/2018

Date of Review	
Family Support Center Name	
Number of FTE's	
Family Support Agency	
DDS Area Office	

A. FAMILY SUPPORT CENTER PRINCIPLES

1. Accessibility:

Is your Family Support Center able to provide all Center sponsored activities both at the Center and off site in physically accessible settings?
Have you developed networks such as email blasts, groups or call lists as well as materials (posters, brochures, videos, etc.) in order to help generate interest and new referrals to the center?
Notes/Comments:

2. Availability:

How does your Center offer a flexible schedule of Family Support Center services that is responsive to the needs and lifestyle demands of families, which may include some evening and weekend hours?
Notes/Comments:

3. Welcoming Environment:

How does your Center present a "welcoming" environment both in person and over the phone that is genuinely helpful to families?
Does your Center send a "Welcome Letter" and/or other information to a new family that explains the Center's programs and activities and invites them to visit the Center and/or set up a home visit?
What other ideas or initiatives have you utilized to make your Center an inviting and comfortable place for families (i.e. open house, social events, etc.)?
Notes/Comments:

4. Cultural Responsiveness:

Do you have staff members who speak other languages and/or have access to interpreters/translators? Are your brochures and/or other materials in other languages that explain the Center's programs and services?
How do you outreach and provide services to families from diverse cultural, ethnic and linguistic backgrounds within the Center's geographical boundaries?
Have you developed any partnerships with grassroots community organizations or other resources in order to provide culturally responsive services?
Notes/Comments:

5. Geographical Responsiveness:

What strategies have you employed to ensure that families have access to Family Support Center activities and services, including families who live in more remote areas?
Do you vary the venue of trainings and other activities throughout the communities served by the Center and/or provide transportation to events?
Notes/Comments:

6. Support for Families of Individuals across the Lifespan:

How are you offering an array of trainings and support for families at various developmental periods/life stages (information/ fact sheets, support groups, mentoring, etc.)?
What are some of your strategies to enhance Center staff expertise in transition issues and planning in order to support and mentor individuals (from ages 14-22 years) and their families?
What are some of the specific trainings and/or groups you initiated to support families through various transition points in their lives?
Notes/Comments:

7. Family Input and Satisfaction:

What are some of the ways you encourage active family involvement and consultation in identifying interests and needs for center trainings, activities and services?
Do you ask people routinely for feedback regarding specific services, trainings, activities and initiatives?
Notes/Comments:

B. SERVICES AND PROGRAM ACTIVITIES

1. Service Navigation:

What has the Center staff learned most from providing service navigation for families of children and adults that assists them in problem-solving and navigating the service system to find services and supports?

How has the development of a family support plan with each family receiving service navigation helped to identify and address their priority needs?

In what ways does the Center support staff development? How does the center foster relationships of center staff with both generic organizations and state resources that will lead to greater access for individuals and families?

Notes/Comments:

2. Administration of Flexible Allocations:

Does the Center administer flexible funding allocations by issuing checks in a timely fashion?

Does the Center complete the Flexible Funding Expenditure Plan to record information about the use of flexible funding by families?

Does the Center have internal policies and procedures for the administration and tracking of flexible funding allocations in compliance with DDS established guidelines?

Does the Center offer families choices in how they receive their flexible funding, including stipend, reimbursement or payment to third party?

Notes/Comments:

3. Parent Networks and Mentoring:

How does your center promote parent networks and mentoring, such as parent support groups, parent connections (1:1 matching) and sibling support opportunities, as well as parent involvement in organizing or leading activities, etc.?

Does your Center connect families with other families in both formal and informal ways such as coffee hours and during social/recreational activities for their children?

Notes/Comments:

4. Information and Referral:

How does your Center provide timely and quality I & R services to families of children and adults? This would involve assisting families in identifying resources and service options available in their local communities, including maximizing other financial and/or state services that families may be eligible.

How has your Center utilized technology to provide a variety of ways to share information with families, including the development of an agency website, on-line newsletters, training calendars, etc.?

How do you maintain a "library" of resources such as helpful websites, fact sheets, community resources, information technology resource options, books, videos, etc.?

Notes/Comments:

5. Family Trainings:

How do you ensure that families know about training opportunities provided by your Center and other community organizations?

Are you offering at least six trainings per year that address common topical areas that are relevant to families across the lifespan, i.e. public benefits, transition planning, educational rights, guardianship, etc.?

Are you able to offer respite or child care to make it easier for families to attend trainings? How do you share information with families who are unable to attend trainings in person?

Notes/Comments:

6. Social/Recreational Opportunities:

What are the variety of social/recreational opportunities the Center offers, including those in partnership with other providers and community resources (e.g. YMCA, recreational centers, neighborhood community centers, Boys and Girls Clubs, etc.)?

Does the Center offer opportunities for individuals with disabilities to build their social capital via active engagement in their local community? How does the Center support the successful development of relationships and friendships between people with and without disabilities?

How does the Center support families who want inclusive social/recreational opportunities with other community organizations? How has the Center helped reduce barriers to participation?

Notes/Comments:

7. Community Connections and Partnerships:

How have you been able to leverage community affiliations and connections to augment services and supports? Has your Center been able to recruit volunteers and student interns from local colleges, high schools and other community resources to support Center activities?

Can you share examples of partnerships that your Center has established with other state and grassroots organizations in order to expand opportunities and services for individuals and families?

Does your Center engage individuals with disabilities in volunteering experiences and giving back to their communities?

Notes/Comments:

C. FAMILY SUPPORT CENTER FEEDBACK:

What does the Family Support Center see as its greatest challenges or needs in meeting specific program goals/outcomes outlined in the FSC Quality Review?

What support or assistance would be most helpful to the Family Support Center in achieving success? Please specify below.

Notes/Comments:



Family Support Center Quality Review Summary

Participants In Attendance at Meeting	
Family Support Center:	Area Office/Regional Office:

Family Support Center Strengths/Accomplishments:

Plans for Development or Improvement:

Focus Area	Action Steps	Target Date
1.		
2.		
3.		
4.		
5.		

Print Family Support Staff Name	_____	Date Signed	_____
Family Support Staff Signature	_____		
Print DDS Area Office Staff Name	_____	Date Signed	_____
DDS Area Office Staff Signature	_____		

Family Support Center Quality Review Progress Updates

Progress Updates Below:

Date of Review:

Focus Area 1:

Focus Area 2:

Focus Area 3:

Focus Area 4:

Focus Area 5:

Progress Updates Below:

Date of Review:

Focus Area 1:

Focus Area 2:

Focus Area 3:

Focus Area 4:

Focus Area 5:

Massachusetts Department of Developmental Services

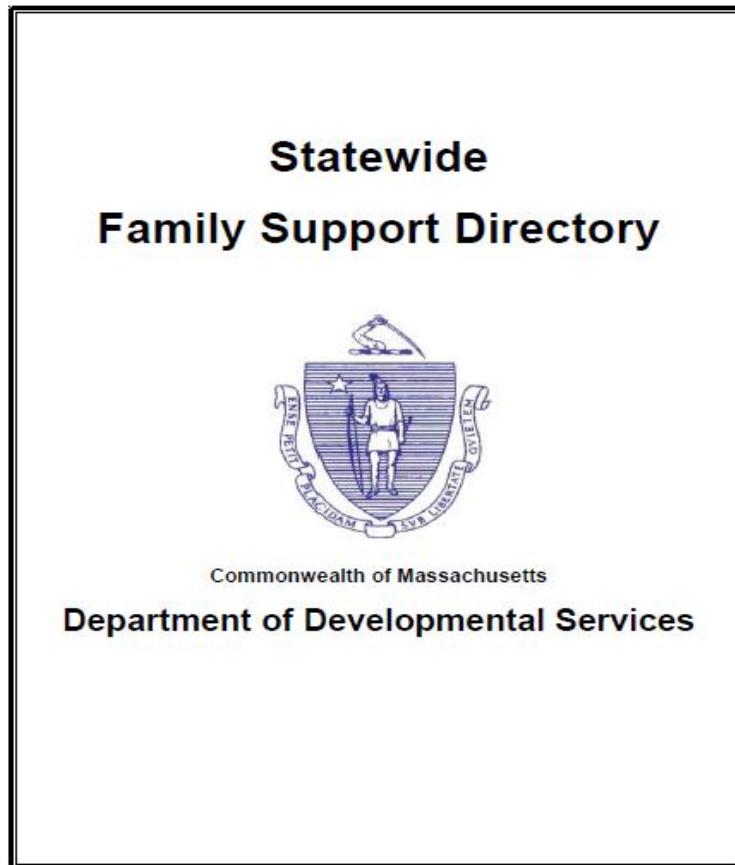
Section: XIV - Other Family Resources

Agency/Program	Telephone	Website	Description
Advocates for Autism of MA (AFAM)	781-891-6270	www.afamaction.org	Advocacy group established to raise awareness of the needs of individuals with Autism and their families, to enhance their lives in their communities.
Arc of Massachusetts	781-891-6270	https://thearcofmass.org/	The Arc of Massachusetts provides education and systems advocacy to consumers, families, human services organizations, the public, legislators, other public officials, and the executive branch.
Asperger/Autism Network (AANE)	617-393-3824	www.aane.org	Helps people with Asperger Syndrome and other similar Autism Spectrum profiles build meaningful, connected lives by providing information, education, community, support and advocacy
Autism Commission of MA	617-624-7848	https://www.mass.gov/orgs/autism-commission	The Commission is charged with investigating the range of services necessary for individuals with ASD to achieve full potential across their lifespan.
Autism Housing Pathways		http://autismhousingpathways.org	Autism Housing Pathways (AHP) was created to provide information, support and resources for families who seek to create secure, supported housing for their adult children with disabilities.
Autism Insurance Resource Center	781-642-0248	www.disabilityinfo.org/arica/	A resource for consumers, providers, clinicians, employers, and educators on issues related to medical insurance for autism treatment.
Best Buddies Massachusetts	866-332-8339	www.bestbuddiesma.org	The mission of Best Buddies is to enhance the lives of people with intellectual disabilities through opportunities for one to one friendship and integrated employment.
Children & Youth With Special Health Care Needs Program/DPH	800-882-1435	www.mass.gov/dph	The Division for Children & Youth with Special Health Needs at the Massachusetts Department of Public Health works with families, providers, and others to support children and youth with special health needs ages birth to 22 and their families.
Commission on the Status of Grandparents Raising Grandchildren	617-748-2454	Colleen.pritoni@state.ma.us	Commission's purpose is to serve as a "resource to the Commonwealth on issues affecting grandparents raising grandchildren". Commission has open meetings monthly across the state, posted at www.mass.gov/elders
Community Gateway		www.communitygateway.org	Provides Central Massachusetts with an internet gateway to local and worldwide disability resources and events, and also a statewide email support group.
Disability Law Center	800-872-9992	www.dlc-ma.org	Provides free legal assistance and training to people with disabilities throughout the state in special education, accessibility and discrimination.
EI Parent Leadership Project	877-353-4757	https://eiplp.org/	The Parent Leadership Project was originated by parents and is staffed by parents whose children have received Early Intervention Services.
Exceptional Lives - MA	844-354-1212	ma.exceptionallives.org/	Non-profit agency that provides information for parents/caregivers of children & adults w/disabilities, including interactive How-to Guides, Resource Directory and Personal Support.
Family Ties	800-905-8437	www.massfamilyties.org	A statewide information, referral and parent-to-parent support network. Publish comprehensive, free resource guide by download or mail.
Federation for Children with Special Needs	800-236-7210	www.fcsn.org	Provides information, support and assistance to parents of children with disabilities, their professional partners, and communities through its website, publications, phone consultations, conferences, workshops, etc.

Institute for Community Inclusion	617-287-4300	www.communityinclusion.org	Supports the rights of children and adults with disabilities to participate in all aspects of the community. Offers training and technical assistance, educational employment, and recreation and living options.
Agency/Program	Telephone	Website	Description
MA Developmental Disabilities Council	617-770-7676	www.mass.gov/mddc	Promotes opportunities for people with developmental disabilities to enhance independence, productivity, integration, and inclusion, including conference funding.
MA Down Syndrome Congress	800-664-6372	www.mdsc.org	Statewide parent organization which holds annual conference, picnic and workshops throughout the year. Publishes a newsletter for parents and maintains a list of parent support groups.
MA Sibling Support Network	617-807-0558	info@masiblingsupport.org	Committed to supporting brothers and sisters of people with disabilities by creating welcoming communities for siblings across the lifespan.
MASS 2-1-1	877-211-MASS	www.mass211.org	MASS 2-1-1 was created and staffed by United Way. This 24/7 service is a resource to connect callers to information about critical health and human services programs.
Mass Options	800-422-6277	www.Mass.Options.org	Trained specialists at Mass Options provide referrals that best fit your individual needs by phone or online chat 7 days a week-8:00 am to 8:00 pm
Massachusetts Advocates for Children	617-357-8431	www.massadvocates.org	Free legal services for income-eligible families on educational issues for children 2-22. Advocacy for parents, including Autism Special Education Legal Support Center.
Massachusetts Families Organizing for Change (MFOFC)	800-406-3632	www.mfofc.org	MFOFC is a statewide grassroots coalition of families dedicated to individual and family empowerment and social inclusion via advocacy and family leadership training.
Massachusetts Family Voices	800-331-0688 x301	www.massfamilyvoices.org	The goal of MA Family Voices and the MA Family to Family Health Information Center is to assist families in making informed choices about care for their children and youth with special health care needs.
Massachusetts Immigrant and Refugee Coalition	617-350-5480	www.miracoalition.org	MIRA is the largest coalition in New England promoting the rights and integration of immigrants and refugees.
MASS-MA Advocates Standing Strong	866-426-2253	www.massadvocatesstandingstrong.org	A statewide self-advocacy organization to ensure that people with intellectual and developmental disabilities are treated equally. Its mission is to empower self-advocates through education.
New England INDEX	800-642-0249	www.disabilityinfo.org	Free information and referral about programs and services to individuals with disabilities in Massachusetts.
Office of Attorney General (MA)	617-727-2200	www.mass.gov/ago	Office of Attorney General has Emergency Planning Guide for Parents with Uncertain Immigration Status and information on Cyber Crime and Internet Safety for kids and adults.
Parent/Professional Advocacy League	Toll Free 866-815-8122	www.info@ppal.net	PPAL is a statewide family organization dedicated to improving the mental health and well-being of children, youth and families through education, advocacy and partnership.
Rewarding Work Respite Directory		www.massrespitedirectory.org	This directory helps families to find respite workers when they're needed. Families can search for individual workers or post a job opening using the password "ddsconnect".
Special Olympics Massachusetts	508-485-0986	www.specialolympicsma.org	Provides year-round sports training, athletic competition, and other health-related programming for athletes with intellectual disabilities.
SPED Child & Teen	508-303-3424	http://www.spedchildmass.com	Compiles a wide array of disability related events and information throughout Mass.

A. Statewide Family Support Directory

The Statewide Family Support Directory is a great resource to help families and support professionals to access Family Support Centers and Autism Support Centers and other family support programs in their area. It also includes contact information on DDS Area, Regional and Statewide offices. The Directory is widely disseminated by DDS, its service providers, family advocacy organizations and is posted on the DDS website: www.mass.gov/dds



Introduction

The Department of Developmental Services (DDS) provides funding for family support programs and services across the state designed to provide information, assistance, and an array of supportive services to families with children and adults with disabilities who are living at home.

The Department views families as the best natural resource for individuals with disabilities and recognizes the importance of developing strong partnerships with families. Families know their children and their own strengths and needs. The design of the Family Support Services is to supplement and build upon the capacities of families, and should be flexible and respectful of cultural, economic, social, and spiritual differences.

Any family can contact one of the Family Support Centers listed in this Directory for information and referral services. However, to receive other DDS funded family support services, an individual must be found eligible for DDS services and must be living at home with their family. The Regional Eligibility team intake and eligibility process is conducted by a Regional Eligibility Team located at one of the four DDS regional offices listed in this Directory. The process begins by the submission of an Eligibility Application Form. More information about the eligibility process as well as the application forms can be found on the DDS website, www.mass.gov/dds. Eligibility Application Forms can also be obtained at any of the DDS Area or Regional offices.

The Department is pleased that you have received a copy of this *Family Support Directory* and hope it will be helpful to you in locating services and supports.

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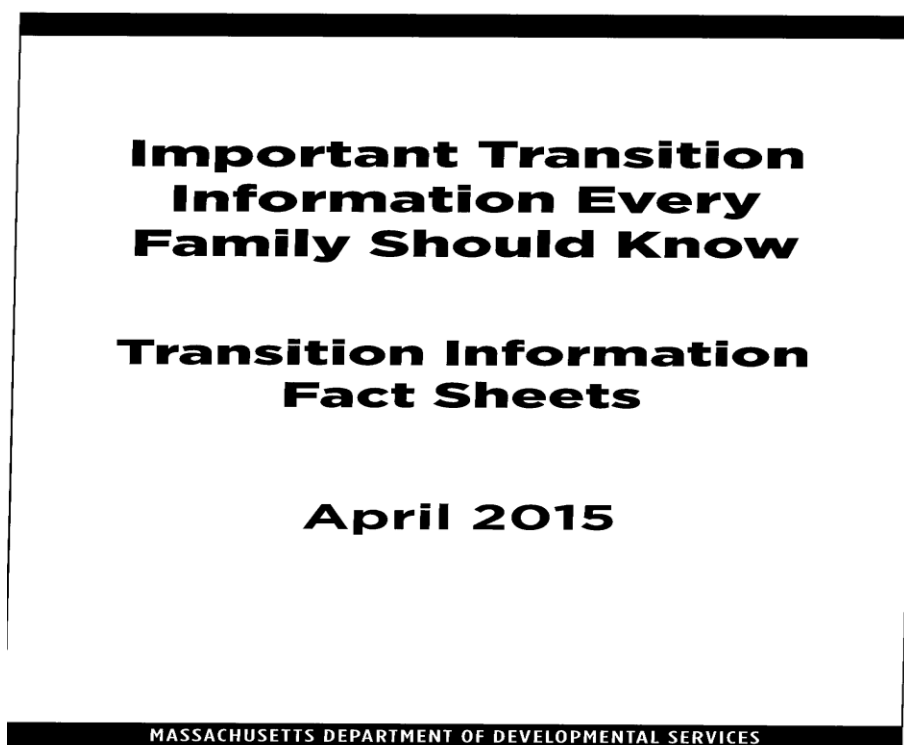
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B. Transition Information Fact Sheets – Listing

The Department initiated a strategic planning process in 2011 to seek input and guidance from individuals with intellectual disabilities and their families about their family support services in order to inform future policy and program directions. Based on the number of responses from families and others interested in the transition of individuals with intellectual disabilities from school to adult life, the Department of Developmental Services (DDS) organized a transition workgroup which came up with a series of recommendations. One recurring issue that surfaced was the need for easy access to information about transition and help with navigating the maze of human services. Towards this goal, DDS has compiled a series of transition fact sheets in April 2015 called **“Important Transition Information Every Family Should Know”**.

On the next page is the Table of Contents that provides the various titles for each of the twenty-six fact sheets. The fact sheets are available in both English and Spanish and can be found at <http://www.mass.gov/eohhs/docs/dmr/dds-transition-sheets-2015.pdf>

The fact sheets can be used singularly or in various combinations and sequences depending on the needs of the audience. Please keep in mind that the transition process can be complex. The fact sheets are meant to support transition conversation and planning with the individual, family and the Area Office.



Transition Information Fact Sheets

Table of Contents

GETTING STARTED

- ☐ 1. Developing a Vision
- ☐ 2. Person-Centered Planning
- ☐ 3. Letter of Intent
- ☐ 4. Transition Timeline
- ☐ 5. Student's Role in Transition
- ☐ 6. Family's Role in Transition
- ☐ 7. Tips for Maximizing the Educational Process

TRANSITION ESSENTIALS

- ☐ 8. Federal and Massachusetts Laws on Transition
- ☐ 9. Chapter 688/Turning 22
- ☐ 10. DDS Adult Eligibility
- ☐ 11. Supports for Adults with Autism Spectrum Disorder
- ☐ 12. MASSCAP and Prioritization
- ☐ 13. Supports Intensity Scale (SIS)
- ☐ 14. Adult Services
- ☐ 15. Participant-Directed Supports Program
- ☐ 16. Agency With Choice Program: Co-Directed Supports
- ☐ 17. Employment First Initiative
- ☐ 18. Transportation
- ☐ 19. Family Support, Recreation, and Friendships
- ☐ 20. State Agency Resources
- ☐ 21. Residential Alternatives
- ☐ 22. DDS Home and Community-Based Waiver Overview

OTHER RESOURCES & CONSIDERATIONS

- ☐ 23. Age of Majority, Guardianship, and Alternatives
- ☐ 24. MassHealth Benefits
- ☐ 25. SSI Benefits
- ☐ 26. Special Needs Trusts

C. DDS Home & Community-Based Waiver Overview

WHAT are the Home and Community-Based Services Adult Waiver Programs?

The Department of Developmental Services (DDS) Home and Community-Based Services (HCBS) Waivers are a way for individuals to receive services in their home community instead of an institution. These waivers are a federal and state partnership. They are run by DDS on behalf of the Commonwealth of Massachusetts through MassHealth (Medicaid). Federal reimbursement to the Commonwealth of Massachusetts for waiver services helps support the availability and expansion of DDS supports. The waivers may provide participants some level of protection of their services.

WHO is eligible for HCBS Waivers?

To be eligible for the waiver program, you must meet these federal requirements:

- Apply to become a waiver participant;
- Be a person with an intellectual disability as determined by DDS;
- Be eligible for and enrolled in the correct MassHealth category;
- Be at least 22 years of age;
- Be eligible for admission to an Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/ID);
- Agree to receive services in the community rather than an institution; and
- Be assessed by DDS to need one or more waiver services.

HOW can I apply?

In order to apply, you need to fill out a waiver application. Your DDS Area Office can help you and can discuss the timing of your application. DDS will conduct an assessment of your needs, assign you a priority for services, and send you a letter to let you know if you are eligible for one of the waiver programs.

WHEN enrolled in one of the DDS Adult Waivers, can I still receive other Medicaid services?

Yes, you can be enrolled in the waiver program and still receive other Medicaid program services such as medical care, nursing care, home health aide services, personal care attendant services, and any other medically necessary service that is available through the Medicaid Program State Plan.

WHAT happens if I do not enroll or cannot enroll?

DDS will work with you and your family to determine if you need to enroll in the waiver program to obtain or keep services from DDS and help you resolve waiver eligibility issues.

WHAT if my needs change?

If your needs change, you will be referred for an assessment to determine if you need additional or different services. This may result in eligibility for and enrollment in a different waiver.

WHAT services can I receive in the DDS Adult Waiver Programs?

INTENSIVE SUPPORTS WAIVER PROGRAM

The **Intensive Supports Waiver Program** provides services for individuals with intellectual disability age 22 and older with an intensive level of support needs, requiring supervision or support for 24 hours a day, seven days per week, due to significant behavioral, medical, and/or physical support needs and the absence of available, natural, generic, and Medicaid services. Waiver services offered may differ depending on location of waiver participant.

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Chore, Community Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Live-In Caregiver, Peer Support, Residential Habilitation, Respite, Specialized Medical Equipment and Supplies, Stabilization, Transitional Assistance Services, Transportation , Vehicle Modification, and 24 hour self-directed home sharing support.

COMMUNITY LIVING WAIVER PROGRAM

The **Community Living Waiver Program** is for individuals who can live in their family home, in the home of someone else, or their own home, and do not need supervision 24 hours a day, seven days a week due to the combination of natural, generic, and Medicaid services.

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Chore, Community Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Live-In Caregiver, Peer Support, Respite, Specialized Medical Equipment and Supplies, Stabilization, Transportation, and Vehicle Modification

ADULT SUPPORTS WAIVER PROGRAM

The **Adult Supports Waiver Program** is for individuals who can live in their own home or apartment or family home due to the combination of strong natural/informal generic and Medicaid services.

Waiver services offered include:

Adult Companion, Assistive Technology, Behavioral Supports and Consultation, Chore, Community Based Day Supports, Day Habilitation Supplement, Family Training, Group Supported Employment, Home Modification and Adaptations, Individual Goods and Services, Individualized Day Supports, Individualized Home Supports, Individual Supported Employment, Peer Support, Respite, Specialized Medical Equipment and Supplies, Stabilization, Transportation, and Vehicle Modification

HOW can I find out more about the DDS waiver program?

Your DDS Area Office can provide you with additional information about the services offered through the waiver program. You can also email the Waiver Management Unit at DDS-DL-WaiverManagementUnit@MassMail.State.MA.US or visit the DDS website at: www.mass.gov/dds

D. STRATEGIES to Consider For Connecting People With/Without Disabilities

There are many possible ways for people to connect (or re-connect) with each other. Being together at the same time and in the same place with others who share your interests is not a guarantee that friendships will blossom. But this connection is an essential ingredient! Here are some strategies we may be able to use in our professional (and personal) lives to help people with and without disabilities benefit from getting to know each other.

- I. **Deepening Existing Relationships in places already frequented:** Don't overlook the people and places that an individual already knows and spends time with and at. This includes their workplace! Even if there are not yet friendships there, there are real possibilities of deepening connections where someone may already be comfortable, confident and known.
- II. **1-to-1 Match Making:** Some approaches seek 1-to-1 matches between people with and without disabilities right from the start. These include:
 - Citizen Advocacy (<https://www.nqcitizenadvocacy.org/>): Staff from NQCA would be happy to share information on how their program works. There is also a great webinar that may be of help (<http://creatingourcommonwealth.org/learning-journey/>).
 - Community of Friends (<http://www.betacomm.org/volunteer-oportunites/>): For decades, Beta Community Partnerships has been matching adults they support with volunteer members of their communities, based on shared interests.
 - Big Brother/Big Sister (<http://www.bbbs.org/>): Although not disability-specific, BB/BS has often made successful matches between people with and without disabilities. There are chapters all over Massachusetts.
- III. **"Group matching":** Another approach is to gather a group of people with and without disabilities to socialize together, with a goal for also evolving 1-to-1 relationships:
 - Club 21 (<https://alternativesnet.org/ways-to-help/be-an-ambassador/club-21/>)
- IV. **Become a member of an organization/club/association/ group** that shares the same interest(s)/need(s). Becoming a "member" of a formal or informal group is the entry for many friendships:
 - **Recreational/social/civic organizations** abound in our communities. You can find out about these opportunities in several ways:
 - Community "mapping" activities that involve staff and people served.
 - Meetup (<https://www.meetup.com/>) is a site that lists dozens of different interests and can be used to find other folks who share the same passion.
 - Widening the Circle's website includes a section with lots of links to activities that people with and without disabilities can enjoy together (<http://thearcofmass.org/resources/recreation/>)
 - **Faith-based groups.** Surveys show that many people with disabilities have been denied the opportunity to participate in the religion of their choice. And faith-based organizations have a variety of activities within their scope (services, choir, childcare, social events, community service, adult bible study, etc.) in which people with and without disabilities can connect. Some efforts have been formalized:
 - Bridges to Faith/New Bedford (www.bridgestofaith.org)
 - Spiritual Connections/Fall River (<http://peopleinc-fr.org/programs/spiritual-connections/>)
 - **"Needs"-based groups.** Fun, civic-mindedness and spirituality are not the only entrees to membership that can grow into friendships. Many people get connected with others who are trying to deal with similar challenges in their life, including:
 - Weight Watchers (<https://www.weightwatchers.com/us/find-a-meeting/>) or TOPS (<http://www.tops.org/TOPS/FindAMeeting>) for folks struggling with their weight.

- Alcoholics Anonymous (http://www.aa.org/pages/en_US/find-aa-resources) or Al-Anon (<http://al-anon.org/find-a-meeting>) for those living with addictions issues.
 - Bereavement groups (<http://www.hellogrief.org/resources/massachusetts/>)
 - **Tips to improve the opportunities for membership:**
 - **Be sure that the individual is truly interested** in the organization in which he/she is pursuing membership.
 - Make sure that the individual is as aware as possible of **what may be expected from members**.
- This includes:**
- Learning the **jargon/language** used by the particular group. For instance, sailors use a very different set of words/phrases than bird watchers do.
 - **Dress appropriately** to fit in with the group. A member of a hiking club will dress very differently from a choir member.
 - Understand the different **rituals** that are important for true membership in a specific group. This may be especially important in churches, for example.
 - Whenever possible, a **staff person who is familiar/personally involved with the group** that you're supporting someone to join should be tapped for that role. This may mean polling staff outside the individual's immediate circle to find the right person. That person should be the consistent supporter for this purpose; rotating various staff will likely reduce the chances of success.
 - Try to **find someone** (not a staff person in the individual's support organization) **who is already a valued member within the group** in which you are supporting someone to be a member. Successful membership is greatly increased if there is a mentor/champion/sponsor/gate-keeper on the "inside" who can be welcoming and supportive of a new member.

V. **Start a group** for people who may share the same interest(s)/needs: It's possible that there may not be a local group that reflects the interest(s) of the person you support. Consider starting a club/group and Invite people with and without disabilities. (New groups can post on <https://www.meetup.com/>.)

VI. **Tap into existing programs:** There may be some programs in your area that intentionally bring people with and without disabilities together with one of their goals being the development of friendships.

These include, but may not be limited to:

- Best Buddies (www.bestbuddiesmassachusetts.org):
- Unified Sports (Special Olympics) (<https://www.specialolympicsma.org/what-we-do/transformative-education/project-unify/>)

VII. **Learn new skills or seek new knowledge in Community settings.** For instance, learn new cooking skills in an adult-education class at the local HS or Community College instead of at the service agency office or in the group home.

VIII. **Connect with your neighbors:**

- Host neighborhood events (block party/Holiday caroling).
- Bring food/cookies to new neighbors.
- Shovel snow/mow lawns/do errands for elderly neighbors. Or just visit and talk!
- DON'T do stuff that emphasizes differences from neighbors (hosting cookout for multiple group homes instead of inviting neighbors).

IX. **Reconnect with people from the past:**

- Locating old friends (via face-book and other social net-working sites).
- Inviting trusted ex-staff to become voluntarily re-involved (if they left the organization on good terms that do not represent a danger for the individual).

- X. **Using Interns/short-term volunteers:** Many organizations host interns (paid or unpaid) or volunteers in their organizations for relatively short periods of time. Quite often the organizations will use these interns as companions to the people they support, charging them with the responsibility of going on community outings/activities. A better use of a short-term person would be to have him/her help the individual establish membership somewhere in their community and to work as the “introducer” between people the agency supports and other community members. With hard work (and a little luck) the interns work will live beyond their tenure in the form of lasting relationships that they helped facilitate.
- XI. **Additional Resources:**
- “Friends: Connecting People with Disabilities and Community Members”, by Angela Amado at https://ici.umn.edu/products/docs/Friends_manual.pdf.
 - “How to Build Relationships” by Al Condeluci listed on Widening the Circle’s “How To...” webpage at <http://thearcofmass.org/programs/widening-the-circle/how-tos/>.
 - 150 THINGS YOU CAN DO TO BUILD SOCIAL CAPITAL: Social capital is built through hundreds of little and big actions we take every day. We've gotten you started with a list of nearly 150 ideas, drawn from suggestions made by many people and groups. Try some of these or try your own. <https://www.hks.harvard.edu/saguaro/whatyoucando.htm>
 - Widening the Circle’s website at <http://thearcofmass.org/programs/widening-the-circle>.



Created by:
“Widening the Circle, a Project under the auspices
of the Arc of Massachusetts and funded by the
MA Department of Developmental Services



Simply Stated

***“The quantity and quality of your relationships
is important. The more social capital you have,
the healthier you are, the happier you are, the
more you achieve, the longer you live, and the
better the outcomes are in your life.”***

Al Condeluci, Ph.D

Massachusetts Department of Developmental Services
Section: XV - Family Support Fact Sheets

- 1. Family Support Centers**
- 2. Cultural/Linguistic-Specific Family Support Center**
- 3. Autism Support Centers**
- 4. Intensive Flexible Family Support Services (IFFS)**
- 5. Medically Complex Programs**
- 6. Family Leadership Programs**

Massachusetts Department of Developmental Services

FAMILY SUPPORT FACT SHEETS

#1

Family Support Centers

Family Support Centers (FSC) have a local presence and act as a hub for offering a wide range of general family support services and activities to families of children and adults living at home who are eligible for DDS services. There is at least one Center in each DDS Area Office across the state. Centers are expected to conduct broad outreach and provide services to families from diverse cultural, ethnic and linguistic communities in the geographic area they are serving. This involves creating partnerships with community organizations and connecting with other resources in order to provide culturally responsive services.

Centers are expected to encourage active family involvement and consultation to identify interests and needs in developing activities and service options. Family Support Center staff provide an array of services and supports to families that include: information and referral, service navigation, support groups, trainings, parent networking and mentoring, administration of flexible funding allocations, facilitation of social/recreational events, and access to technology among other activities.

What's unique about Family Support Centers?

- General Center services, such as Information and Referral, are available to all families. Families are sent a "Welcome to DDS" flier with information about their local Family Support and Autism Support Centers at the time their son or daughter is found eligible for DDS services.
- Center staff are expected to develop expertise and be knowledgeable about local, state and federal resources, assist families in identifying resources and service options available in their local communities, and help them navigate the service system.
- Although Family Support Centers offer the required array of services specified below, each Center also develops unique services, trainings and activities based on individual and family interests and needs across the lifespan.

ACTIVITY CODE: 3770 **MEDITECH ENROLLMENT:** YES-Only for Individuals receiving Extended Service Navigation

REIMBURSEMENT: Monthly Accommodation Rate based on the number of Service Navigator full time equivalent staff (FTEs)

SERVICES AVAILABLE: Information and Referral, support groups, small group activities, trainings, parent networking and service navigation, both on a short-term and expended bases, and administration of flexible funding. This is not an exhaustive list as each Center offers a variety of services.

ARE REFERRALS REQUIRED TO ACCESS FAMILY SUPPORT CENTERS? No referral is required to access the FSC for Information and Referral, trainings, small group activities or short-term service navigation. Referrals from the DDS local Area Office **ARE** required for Extended Service Navigation. The Area Office can call the Center directly to enroll a family, or the FSC can contact the Area Office suggesting that a family would benefit from receiving Extended Service Navigation. Anyone receiving Extended Service Navigation must be recorded on the Monthly Service Delivery Report and have a Family Support Plan.

ELIGIBILITY CRITERIA: Individuals who have been determined eligible for DDS services; and live with their family, can access these services. Any individual and family can access Information and Referral and other general services, and can also seek assistance from Center staff to help them apply for DDS eligibility, as some services will require DDS eligibility.

PROGRAM AVAILABILITY: Family Support Centers are located across the state, with at least one Family Support Center for each Area Office. A listing of Family Support Centers can be found in the Statewide Family Support Directory at www.mass.gov/dds. Families often choose the FSC closest to their home, but are not required to make that choice. Information and referral, support groups, some small group activities, family training, parent networking and short term service navigation are the services that require no authorization and can be accessed at any FSC in the state. For example a family can attend training in any FSC regardless of their geography if there is capacity. Certain services requiring additional resources must be authorized by the individual's Area Office.

Cultural/Linguistic-Specific Family Support Centers

Cultural/Linguistic-Specific Family Support Centers have been established to provide access and be responsive to the unique needs of diverse cultural group(s) in specific areas of the state, as well as conduct outreach to other cultural/linguistic groups of families across the state. These Centers offer many of the same services as the regular Family Support Centers, but also address the specific needs of individuals and families from diverse cultures. Families receiving services are typically those, for whom English is not their primary language, face linguistic barriers in accessing services, and require more individualized and specialized assistance.

What's unique about Cultural/Linguistic-Specific Family Support Centers?

- Cultural/Linguistic-Specific Family Support Centers are intentionally designed to address the needs of a specific cultural and linguistic family group (or groups) in an area or region of the state, including outreach and partnerships with community grassroots organizations.
- Program Staff are bilingual in the primary language(s) spoken by the families and have a good understanding of the cultural values, beliefs and traditions of the families being served.
- These Centers provide more individualized service navigation and guidance that responds to family-identified needs in priority areas like housing, employment, finances, health care, and education. This requires skilled staff with strong experience and expertise in accessing entitlements and other generic resources.
- These specialized Centers encourage active family involvement and consultation to identify interests and needs in developing and prioritizing activities and service options.

ACTIVITY CODE: 3771 **MEDITECH ENROLLMENT:** YES-Only for individuals receiving Extended Service Navigation

REIMBURSEMENT: Monthly Accommodation Rate based on the number of Service Navigator full time equivalent staff (FTEs)

SERVICES AVAILABLE: Information and Referral, family training and parent networking, community connections and resources, service navigation, administration of flexible funding, translation and interpretation, and social opportunities to connect with families served by the Center.

ARE REFERRALS REQUIRED TO ACCESS FSC? No referral is required for families to access the Center for Information and Referral, trainings, small group activities or short-term service navigation. Referrals **ARE** required for **Extended Service Navigation**. The Area Office can contact the Center directly to enroll a family. These Centers are expected to engage in active outreach to the cultural and linguistic groups in their communities to help identify individuals and families not connected in services and assist them with the DDS eligibility application process.

ELIGIBILITY CRITERIA: Individuals who have been determined eligible for DDS services and live with their family, can access the services of Cultural/Linguistic specific Family Support Center. Any individual and family can access Information and Referral and other general services, and can also seek assistance by Center staff to help them apply for DDS eligibility, as some services will require DDS eligibility.

PROGRAM AVAILABILITY: There are currently ten Cultural/Linguistic-Specific Family Support Centers in the state. However, all Family Support Centers 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. A listing of all Centers can be found in the Statewide Family Support Directory at: www.mass.gov/dds

Autism Support Centers

Autism Support Centers provide an array of services and supports to children and adults with Autism Spectrum Disorders (ASD) and their families. Services include information and referral, support groups, access to the latest information on Autism, family trainings, parent networking and mentoring, and social/recreational events, among other activities. These Centers work to establish a local presence and have staff with expertise in ASD. It is expected that Autism Support Centers will conduct broad outreach and provide services to families from diverse cultural, ethnic and linguistic communities in the geographic area they serve. This may involve creating partnerships with community organizations and other resources in order to provide culturally responsive services. Centers are expected to work collaboratively with their local DDS Area Offices to respond to the needs of families.

What's unique about Autism Support Centers?

- In addition to providing an array of information and referral services, resources and supports to children with ASD and their families, the Autism Support Centers have responsibility to offer assistance and support to DDS eligible adults with ASD who do not have an intellectual disability and their families.
- Autism Support Centers provide both consultation and coordination for families related to their family member's ASD diagnosis, including helping individuals and families to connect with local resources and healthcare providers with experience in serving children and adults with ASD.
- These Centers have Autism Support Brokers positions who specifically work with families of children (0-9 years) who participate in the statewide Children's Autism Waiver Program which provides a comprehensive array of in-home behavioral supports and other ancillary services.

ACTIVITY CODE: 3772 **MEDITECH ENROLLMENT:** NO-(NOTE: There are different requirements for children enrolled in the Children's Autism Waiver Program)

REIMBURSEMENT: Monthly Accommodation Rate based on the number of full-time equivalent staff positions (FTEs)

SERVICES AVAILABLE: Information and referral, family training, parent networking, social skills and recreational programs, help navigating services, and a variety of peer, skills development and social opportunities for adults with ASD. Autism Support Broker services are provided for children and families who participate in the Children Autism Waiver Program. This is not an exhaustive list as each Center offers a variety of services and activities.

ARE REFERRALS REQUIRED TO ACCESS AUTISM SUPPORT CENTER? No, individuals with ASD and families can access the Autism Support Center directly for general information and referral, family trainings, and some of the other support services offered by the Centers. There may be specific services that require DDS eligibility. Area Offices routinely refer individuals and families to the Autism Support Center(s) in their area.

NOTE: There are specific eligibility criteria and enrollment processes for children who participate in the Children's Autism Waiver Program and receive Autism Support Broker Services from the Autism Support Centers. More information about the Children's Autism Waiver Program and the eligibility process can be found on the DDS web-site.

ELIGIBILITY CRITERIA: Any individual and family can access Information and Referral and other general services, at the Autism Support Center and can also seek assistance by Center staff to help them apply for DDS eligibility. DDS eligibility is not required except for children who participate in the Children's Autism Waiver Program.

PROGRAM AVAILABILITY: There are currently 7 Regional Autism Support Centers across the state. See the Statewide Family Support Directory at www.mass.gov for this listing and specific contact information.

Intensive Flexible Family Support Services (IFFS)

Intensive Flexible Family Support programs are designed to help support families with one or more members with a disability who are experiencing significant challenges, which are causing the child/individual to be at risk of out-of-home placement. This is a time-limited (approximately 6 to 18 months) and goal-oriented service providing more focused and intensive supports in response to identified areas of need in order to build family capacity to support their child/young adult at home.

What's unique about Intensive Flexible Family Support Services (IFFS)?

- IFFS navigators are extremely knowledgeable and adept at identifying and facilitating referrals and access to other clinical and generic services that are beneficial to the child and family.
- IFFS programs are unique in their ability to build family capacity by helping the family with support to gain confidence in making connections for the future as well as implementing programs and strategies through modeling and guidance.

ACTIVITY CODE: 3773 **MEDITECH ENROLLMENT:** YES

REIMBURSEMENT: Daily Rate per Enrollee

SERVICES AVAILABLE: Development of a Family Support Plan which outlines specific goals, objectives, time-lines and responsible parties. Provision of intensive staff assistance and supports to address identified needs and work on established goals and objectives to enable the individual to remain at home. Identification and facilitation of referrals and access to other services that may be of benefit to the child and family. Assistance to the family in the coordination of services that may include medical services, therapies, behavioral training, educational services, etc. Ability to provide flexible funding allocations to support the family in their care giver role when needed.

ARE REFERRALS REQUIRED TO ACCESS IFFS? Yes. IFFS is purchased as a discrete program service at either the Regional or Area Office level. It is a closed referral program through the local DDS Area Offices.

ELIGIBILITY CRITERIA: Children/young adults and families who receive services through an IFFS program will meet the following criteria:

- The individual is eligible for DDS Children's services.
- The individual is between the ages of 3 up to 22 years and livings with their family at home.
- The individual is at risk of out-of-home placement due to the family's difficulty in meeting the child's extensive care needs and/or the family is experiencing excessive stress or destabilization.
- The individual is not under the custody of the Department of Children and Family Services (DCF) or the Department of Youth Services (DYS). Children in a pre-adoptive home may be eligible for participation in this service.

PROGRAM AVAILABILITY: IFFS Programs are available across the state. Many programs serve specific DDS Area Office while others operate on a Regional level. The local DDS Area Office or Regional Family Support Director can provide additional information and answer questions about the IFFS program in your specific area.

Medically Complex Programs

Medically Complex Programs are Regional programs that provide a family-driven model of care which supports families with children and young adults from age 3 up to 25 years of age who have significant cognitive, physical, and complex health care needs and are living at home. The goal is to provide comprehensive wrap-around supports, which consist of specialized case management activities that help families integrate the variety of resources and supports they are receiving in order to care for their family member at home.

What's unique about Medically Complex Programs?

- The Program Coordinators have both life experience and expertise in accessing supplemental resources and services that enable these individuals with complex medical challenges to live at home and support a meaningful and quality life for all the family members.
- These programs staff can offer valuable information and guidance to the family and the Area Office to support transition planning to adult services when the individual turns 22. They help integrate medical consideration and supports in developing service options, and identify and address other issues that may emerge as the individual enters the adult service system (i.e. guardianship, renewing eligibility for specific services as an adult, adult medical providers, etc.).

ACTIVITY CODE: 3774 **MEDITECH ENROLLMENT:** YES

REIMBURSEMENT: Monthly Accommodation Rate per Enrollee

SERVICES AVAILABLE: Services include Information and Referral, assessment of family needs and strengths, comprehensive service navigation and planning, including development of Family Support Plan, identification of additional in home medical supports, and medical equipment needed, assistance in accessing home/vehicle adaptations; advocacy, and collaboration with school and other providers. Comprehensive Service Navigation for transition-age young adult up to age 25 and their families offers specialized expertise and resource information specific to the individual's medical challenges and supports that will be helpful in the transition planning process to adult life. Administrations of flexible funding allocations to address unmet support needs of families.

ARE REFERRALS REQUIRED TO ACCESS MEDICALLY COMPLEX PROGRAMS? Yes, program services are purchased as a discrete service with designated slots managed at the Regional level by the Family Support Director. It is a closed referral program with referrals made by the local DDS Area Offices.

ELIGIBILITY CRITERIA:

- The child/young adult has been determined eligible for DDS services and has complex medical and developmental needs and lives at home with their family.
- Children starting at age 3, and young adults up to age 25, to facilitate transition planning to adult services.
- Meet one or more of the criteria below that have been established to define medically complex:
 - Presently receiving in-home nursing or eligible for MassHealth continuous nursing services (CNS) as authorized through the Community Case Management Program;
 - Diagnosed with chronic, potentially life threatening medical condition(s) requiring skill nursing assessments and daily technological and/or medical interventions from trained family, support staff, or health professionals

PROGRAM AVAILABILITY: There are five Medically Complex Programs across the state organized by DDS Regions. The specific contact information for these programs can be found in the Statewide Family Support Directory which is posted on the DDS website: www.mass.gov/dds.

Family Leadership Programs

The Family Leadership Program provides education, leadership training and mentoring for families with children and adults with disabilities living in the community. Funded by DDS, the Family Leadership Program is a collaborative partnership with Massachusetts Families Organizing for Change (MFOFC) and host agencies throughout the Commonwealth. Family leadership training and mentoring is developed and provided by family members who have a child or adult family member with a disability.

What's unique about Family Leadership Programs?

- Each Family Leadership program sponsors a Family Leadership Series, which focuses on helping families and individuals develop the vision, knowledge and leadership skills they need to live in their communities as naturally and typically as desired. The Series is an intensive training experience that takes place over several weekends and includes overnight hotel stays. It is free of charge for families to participate, and has been described as transformative and a “game changer” by many participants.
- The Family Leadership projects also sponsor “A Full Life Ahead” series of workshops, designed for parents and caregivers as they plan for the future of their loved one with a disability. These workshops are presented at locations throughout the state on a variety of topics.
- For families with younger children, an Advocacy Bootcamp, has been developed to provide training for parents of young children (birth to age 10) with developmental disabilities, chronic illnesses, and/or complex medical needs. The content focuses on building foundational advocacy skills so that participants can empower their children to lead rich, meaningful, and exciting lives.

Other Family Leadership programs include advocacy events, a housing conference, and other training opportunities in response to local family needs and interests.

ACTIVITY CODE: 3776

MEDITECH ENROLLMENT: NO

REIMBURSEMENT: Cost Reimbursement Contract

SERVICES AVAILABLE: Family Leadership Series, A Full Life Ahead Series, Advocacy Bootcamp, as well as other Regional activities.

ARE REFERRALS REQUIRED TO ACCESS FAMILY LEADERSHIP PROGRAMS? No. Families may participate by direct contact with Family Leadership Coordinators in each Regional Program.

ELIGIBILITY CRITERIA: Due to the intensive nature and capacity of the Family Leadership Series, there is an expectation that priority is given to families of children and adults of all ages who are, or likely will be eligible for DDS services. Most other training opportunities are open to all families with children or adult member with a disability regardless of DDS eligibility status.

PROGRAM AVAILABILITY: There are five family Leadership Programs across the state organized by DDS Regions. The specific contact information for these programs can be found in the Statewide Family Support Directory which is posted on the DDS website: www.mass.gov/dds. Families may also directly contact Massachusetts Families Organizing for Change at www.mfofc.org.

Massachusetts Department of Developmental Services

Section: XVI - Appendix

FORMS: The forms included in this Manual are samples of forms that will be distributed as separate documents for use by Area Office and provider staff.

➤ **Implementation and Guidance**

- A. Vehicle or Home Modification Prior Approval Funding Request Form
- B. Prior Approval Form For Flexible Funding Request Over \$3000.00
- C. Family Support Center/Program Flexible Funding Request Form
- D. Flexible Funding Expenditure Plan
- E. Family Support Plan
- F. Action Plan
- G. Family Support Inventory and Planning Tool

ANNUAL/DATA REPORTS: The Reports included in this Manual are samples of forms that will be distributed as separate documents for use by Area Office and provider staff.

- 1. Family Support Centers
 - **Information and Guidance**
- 2. Autism Support Centers
 - **Information and Guidance**
- 3. Intensive Flexible Family Supports (IFFS)
- 4. Medically Complex Programs
- 5. Family Leadership Programs

<p style="text-align: center;">Implementation Guidance and Considerations For Family Support and Cultural/Linguistic-Specific Family Support Centers And Other Designated Family Support Programs</p>
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Introduction:

This Implementation Guidance has been updated to provide specific information related to the implementation of revisions to the planning forms, including Request and Prior Approval forms for the use of flexible funding allocations. When required, these forms are to be used by DDS Family Support and Cultural/Linguistic-Specific Family Support Centers and other designated family support programs and DDS staff.

Vehicle or Home Modification Prior Approval Funding Request Form
(Attachment A)

- The Vehicle or Home Modification Prior Approval Funding Request Form will be thoroughly completed and submitted to the Area Office Designee, along with the required three bids attached for home modification requests of \$1,000 or more.
NOTE: This Prior Approval Process, including obtaining Regional Office approval and three bids is NOT REQUIRED for modifications that are under \$1,000.00 (e.g. Hand rails for the bathroom which cost \$400 to install).
- The request will be reviewed by the Area Director and the Regional Director/Designee and their signatures are required to constitute approval of this expenditure.
- Verification of completion of the home or vehicle modification will be made in person by the Service Coordinator or Area Office designee and noted on the Vehicle or Home Modification Prior Approval Funding Request Form in the individual's Area Office file.

Prior Approval Form for Flexible Funding Requests Over \$3,000.00
(Attachment B)

- To be used when making a request to authorize flexible funding allocations over \$3,000. This also includes situations when multiple flexible funding allocations issued to an individual/family total over \$3,000 in the same fiscal year.
- The Area Office Service Coordinator should include the total amount of flexible funding requested, including a brief rationale describing the needs of the individual and family and how these additional funds will be used to address those needs.
- The form must be reviewed by the Area Director/Designee and either recommended Yes or No, and then signed by the Area Director/Designee.
- If approved, the form is sent to the Regional Director/Designee for his/her approval or denial.
- The Regional Office notifies the Area Office of its decision and sends the form back to the Area Office, who notifies the Family Support Provider and the family.
- As a reminder, in situations when an Individual/Family may receive flexible funding allocations above \$3000.00 from one year to the next, this Prior Approval Process should be completed annually.

- **NOTE:** When there are more than one individual with a disability in the family household, the \$3,000 Prior Approval Process would apply only on an individual basis if that person received a flexible funding allocation over \$3,000.

Family Support Center/Program Flexible Funding Request Form **(Attachment C)**

- To be used by the Family Support Center/Program or DDS Service Coordinator during the fiscal year to identify an individual/family that is in need of a flexible funding, including a recommended allocation and the purpose of the allocation.
- It must be noted on the form whether it is a regular request, a one-time request or an emergency request.

Regular Request- a routine flexible funding request that would be expected to be annualized

One-Time Request- one-time only funding requested at this time

Emergency Request- this is an urgent request requiring a quick turnaround

- The Area Office Designee will review the request and provide written approval or denial. Verification of the individual's eligibility will be completed prior to approval.
- If approved, the flexible funding request will be forwarded to the Family Support Center/Program. The Family Support Center/Program will contact the family and complete the Expenditure Plan in a timely way, but no later than 30 days (inclusive of all signatures), and submit this signed plan to the Area Office Designee. Upon submission of the Plan, funds can be expended.

Flexible Funding Expenditure Plan: **(Attachment D)**

- To be used with **all** families who receive flexible funding from any Family Support program, including Family Support Centers, Medically Complex Programs, and Intensive Flexible Family Support.
- When an individual/family is prioritized to receive a flexible funding allocation, a discussion needs to occur with the individual/family about how they want to use this funding in accordance to the most current version of the Family Support Guidelines and Procedures (See Section VII). This Plan needs to be completed whether the family is receiving their flexible funding in the form of a cash stipend, reimbursement, or payment to a vendor for allowable services or goods.
- The Flexible Funding Expenditure Plan must be completed and signed by the family (or through verification of the date of discussion and approval by family) and also signed by the provider staff member.
- A copy is sent to the Area Office Designee or Service Coordinator for Area Director signature if required, and to be placed in the individual's file. A copy of this Plan should be provided to the family. The Flexible Funding Expenditure Plan should be attached to the Family Support Plan if the individual/family is receiving extended service navigation.
- For DDS Staff: All individuals who receive a flexible funding allocation need to be enrolled in Meditech Activity Code 3779. This includes both children and adults.

Family Support Plan **(Attachment E)**

The Family Support Plan is required to be completed for individuals/families receiving the following services: a) Family Support Centers- **only** with families referred for **Extended Service Navigation** by the Area Office; b) Medically Complex Programs- with all families referred by the Area Office for comprehensive service navigation; and c) IFFS- all families referred by the Area Office. The Family Support Plan has been designed to be a 'dynamic' planning tool that will record both mutually agreed upon areas of initial focus and activity, as well as updates, progress and other emerging needs.

- Plans need to be developed, signed, and submitted to the Area Office within 45 days of referral. Plan needs to be signed by the individual/family and Family Support staff person, with a copy sent to the Area Office designee or Service Coordinator for signature and for placement in the individual's file. The family must receive a signed copy.
- Progress updates added to the Plan do not need to be sent to the Area Office but should be made available for sharing in monthly or quarterly review meetings with the Area Office.
- If a family will be receiving extended service navigation for more than one year, a new Plan should be developed by the annual anniversary date from when the original plan was developed.
- It is expected that the Family Support Plan will be translated in the written language preferable to the family.

For DDS Staff:

Family Support Plans: When Family Support plans are received by the Area Office, the date that the Family Support Plan was developed needs to be entered into Medi-Tech, after which the Plan needs to be placed in the individual's file.

Service Enrollments in MediTech should be made for individuals receiving the following services. The appropriate Service Codes are indicated below:

- Family Support Centers (Extended Navigation only)- 3770
- Cultural/Linguistic-Specific Family Support Centers (Extended Navigation only) - 3771
- Intensive Flexible Family Support Services- 3773
- Medically Complex Programs- 3774

Action Plan **(Attachment F)**

The Action Plan is an optional form that was developed for use by Family Support Centers with families who receive **short-term service navigation**. If a Provider chooses not to use this Action Plan, the Provider and Area Office should agree on another plan to use in documenting who is receiving Short-Term navigation. Any short-term plan should attempt to capture both the need(s) identified by the family and the focused areas of assistance Center staff will provide in response to those need(s), as well as additional information and supports staff identify that may be helpful to the family. It serves as an 'agreement' between the Center staff and family regarding specific actions and expectations. If a Provider chooses not to use this Action Plan, the Provider and the Area Office should agree on another system to use in documenting who is receiving Short-Term Navigation.

- If a family is seeking short-term navigation assistance and their family member with a disability is not DDS eligible at the time, it is expected that the Family Support Center staff will inform the family about the DDS eligibility process and will provide assistance as needed to help them apply for DDS services or other potential state agency services. One of the expectations of the Center is to be helpful to all families, but if an individual is not found eligible for DDS services, then the level of individualized support the Center staff can provide is limited. However, families can participate in trainings, support groups and other general services provided by the Center.
- “Areas of Focus” for Service Navigation: The ‘status update’ and the ‘comments’ sections are designed to capture the progress and outcome of activities and supports that were implemented to address the identified needs. This may be updated as work progresses with a family or at the completion of the short-term navigation assistance provided. It is expected that if a ‘Focus Area’ is no longer considered relevant, there will be an explanation provided in the comments section. Also, the ‘persons responsible’ for following up on specific activities can include Family Support Center staff, the family, the DDS service coordinator, or other people involved with the family who agree to take on this responsibility.
- A copy of the Action Plan should be shared with families and kept on file at the Center. It will serve as a foundation for service planning and delivery if a family seeks short-term navigation assistance again or if the family is referred for Extended Service Navigation in the future.
- Copies of Action Plans (or an alternative) should be made available to DDS Area Office staff at regularly scheduled program review meetings.
- The Action Plan will be provided both as Word document for individuals to complete manually, as well as in an electronic format which can be completed on the computer.
- It is expected that the Action Plan will be translated in the written language preferable to the family.

Three Types of Plans

PLAN	Who Needs It?	When Due?	Is Family Signature Needed?	Who Gets A Copy?
FLEXIBLE FUNDING EXPENDITURE PLAN (ATTACHMENT D)	Individuals prioritized by Area Office to receive a Flexible Funding Allocation from FS Centers, IFFS, and Medically Complex Programs	Refer to guidance in Section VII – Individual Flexible Funding Allocations	Yes, or date and name of discussion and approval by family noted on plan ***** Note: Plan needs to be submitted to Area Office prior to disbursing funds	Family Area Office
FAMILY SUPPORT PLAN (ATTACHMENT E)	Individuals receiving Extended Navigation from FS Centers; IFFS; Medically Complex Programs	Within 30 to 45 days of referral If extended for more than a year, a New Plan is required by the anniversary date of the original plan.	Yes, by the Individual/ Family ***** Note: Plan also needs to be signed by FS provider and Area Office	Family Area Office
ACTION PLAN NOTE: The use of this exact form is optional but <u>an Action Plan is still required.</u> AREA OFFICE and Provider must agree on another plan to use. (ATTACHMENT F)	Individuals receiving short-term service navigation from FS Centers	Developed at time needs are identified	No	Family; Area Office-made available at regularly scheduled program reviews

NOTE: Both the DESE/DDS Program and the Children's Autism Waiver Program have individualized planning processes. These are described in Section: VIII of this Manual.



Family Support Inventory & Planning Tool **(Attachment G)**

Purpose:

The Family Support Inventory and Planning Tool has been updated as an optional resource tool that staff may use in working with families receiving services in Family Support Centers and Cultural/Linguistic-Specific Family Support Centers, Medically Complex Programs, and Intensive Flexible Family Support programs. However, it is recommended that staff in these programs use this tool, or something similar they may have developed, to assist them in their work with families. Providers are also welcome to modify and customize this Inventory by adding local resources or other questions that may be relevant to the families with whom they work. In the Family Support Programs it is anticipated this will primarily be used with families receiving Service Navigation assistance, either short-term or extended.

All planning with families should be individualized and family-centered with the intent of building upon existing strengths and capacities. With that in mind, this Inventory should be implemented in a flexible, family-friendly way, and can be used by section and/or completed incrementally over time, depending on what will be most responsive to the needs of families. It has been designed as a guide to provide an organized and systematic approach to record information about the services and resources families already have in place, and to help identify other services and benefits for which families may be eligible. It is not intended to be an exhaustive list, but does attempt to provide a comprehensive listing of varied types of resources and supports.

Additionally this Planning Tool is intended to:

- Identify assistance or information families are seeking;
- To be a helpful planning tool and inform goals/areas of focus for Service Navigation; and
- Provide information to Family Support Centers/Programs regarding common training needs and interests among families.

This information is primarily for internal use by family support staff and to support planning activities with a family and copies of these Inventories should be kept on file.



ATTACHMENT A -- (SAMPLE)

VEHICLE OR HOME MODIFICATION PRIOR APPROVAL FUNDING REQUEST FORM

This form must be completed when making a request to authorize funding for a vehicle modification or home modification. This form and cost estimate(s) should be submitted in advance to the Area Director for review and recommendation, and then forwarded to the Regional Office for final approval.

Individual's Name:			
DOB:	Click here to enter a date.	Age:	
DDS Area Office:			
DDS Service Coordinator:			
Family Support Center/Program:			
Staff Person Completing Form:		Date of Request:	Click here to enter a date.
What is the request for?	<input type="checkbox"/> Vehicle Modification <input type="checkbox"/> Home Modification		
Total Modification Cost:	\$	Total Requested from DDS:	\$
If a home modification, does the request include the required three bids?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
If request does not include 3 bids, please explain why?			
Does the request relate directly to the functional needs of the individual?	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Please identify item and explain justification of need:			
Other generic funding resources need to be explored and documented. Please describe resources and funding amounts if applicable.			

Area Director/Designee Recommendation:	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Area Director/Designee Signature:		Date:	Click here to enter a date.
Comments:			

Regional Director/Designee Recommendation:	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Regional Director/Designee Signature:		Date:	Click here to enter a date.
Comments:			

Date signed copy sent back to AO:			
Completed Modification Reviewed by:		Date:	Click here to enter a date.

ATTACHMENT B -- (SAMPLE)

PRIOR APPROVAL FORM FOR FLEXIBLE FUNDING REQUESTS OVER \$3,000.00

This form must be completed when making a request to authorize flexible funding allocations above \$3,000.00. This form, along with other pertinent information (such as Family Support Plan, or Flexible Funding Expenditure Plan), must be submitted in advance to the Area Director for review and recommendation, and then forwarded to the Regional Office for final approval on an annual basis.

Individual's Name:			
DOB	Click here to enter a date.	Age:	

DDS Area Office:	
DDS Service Coordinator:	
Family Support Center/Program:	
Staff Person Completing Form:	

Total Amount of Flexible Funding Requested:	\$	Date of Request:	Click here to enter a date.
Please provide a brief rationale describing the needs of the individual and family and how these additional funds will be used to address those needs:			

Area Director/Designee Recommendation:	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Area Director/Designee Signature:		Date:	Click here to enter a date.
Comments:			

Regional Director/Designee Recommendation:	Yes <input type="checkbox"/> No <input type="checkbox"/>		
Regional Director/Designee Signature:		Date:	Click here to enter a date.
Comments:			

Note: This prior approval is valid only for the current Fiscal Year. If the allocation continues the following year another form will need to be completed.

Date signed copy sent back to Area Office:	Click here to enter a date.
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ATTACHMENT C -- (SAMPLE)

FAMILY SUPPORT CENTER/PROGRAM – FLEXIBLE FUNDING REQUEST FORM

Family Support Request: ☐ Regular Request ☐ One Time Request ☐ Emergency Request

Individual's Name:			
DOB (M/D/YYYY):	Click here to enter a date.	Age:	
Address:			
Telephone #1:			
Telephone #2:			
Email #1:			
Email #2:			
Caregiver Name & Relationship:			
Caregiver Address & Phone (if different):			
Indicate if the family currently has AFC in the family home.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		

DDS Area Office:	
DDS Service Coordinator:	
Family Support Center/Program:	

Allocation:	<u>\$0.00</u>	Date:	Click here to enter a date.
Purpose of Allocation:			

Service Coordinator Signature:	Date: Click here to enter a date.
---------------------------------------	---

Approved by (only need one):

Area Director Signature:	Date: Click here to enter a date.
Supervisor/Area Office Designee Signature:	Date: Click here to enter a date.

ATTACHMENT D -- (SAMPLE)

FLEXIBLE FUNDING EXPENDITURE PLAN

Individual's Name:		DDS Area Office:	
Family Contact:		DDS Service Coordinator:	
Family's Address:	<input type="checkbox"/> New Address	DDS Approved Allocation:	\$
DOB (M/D/YYYY):	Click here to enter a date.	Age:	
Telephone #:		<input type="checkbox"/> Decrease <input type="checkbox"/> Increase	\$
Cell #:		New DDS Approved Allocation:	\$
Email:		FS Center/Program Name:	
		FS Center Staff Person:	

Please indicate how you plan to use your allocation and report the total amount for each category and the specific purpose.						
Category	Allowable Expenditures	Allocation	Increase	Decrease	Date Changed	Purpose/Specific Uses
1	Respite Support					
2	Recreational & Social Inclusion Activities					
3	Child Care					
4	Home Management Support Services					
5	Short-Term Emergency Needs					
6	Specialized Evaluations & Therapeutic Services & Supports					
7	Adaptive Equipment & Supplies					
8	Specialized Nutrition & Clothing					
9	Specialized Utility Cost					
10	Transportation					
11	Personal Growth & Enrichment Activities					
12	Family Training					
13	Educational Consultation & Support					
14	Vehicle Modification					
15	Home Modification					
16	Other Approved Use (Specify):					
Total:		\$	\$	\$	New Total:	\$

I/my family will comply with all DDS requirements for the use of this state funding, which includes adhering to the allowable use of flexible funding, as defined in the *January 2019 Family Support Program Manual and Guidelines*. When hiring support workers directly, my family will take responsibility to provide orientation and training on the specific support needs of my family member, including emergency procedures. My family understands that IRS tax rules and requirements may apply when hiring support workers directly.

Name and Date Plan Discussed with Family:		Date:	Click here to enter a date.
Family Signature:		Date:	Click here to enter a date.
Family Support Agency Staff Name:		Date:	Click here to enter a date.
Family Support Agency Staff Signature:		Date:	Click here to enter a date.
DDS Area Office Name & Signature:		Date:	Click here to enter a date.

ATTACHMENT E -- (SAMPLE)

FAMILY SUPPORT PLAN

	Date Plan Developed: (M/D/YYYY)		Click here to enter a date.
Individual's Name:			
DOB: (M/D/YYYY):	Click here to enter a date.	Age:	
School, Job or Work/Day program			
Spoken Language Preference		Interpreter Needed: <input type="checkbox"/>	
Written Language Preference		Translation Needed: <input type="checkbox"/>	
Address:			

Caregiver Name & Relationship:			
Caregiver Address & Phone (if different):			
Telephone:			
Email:			
Spoken Language Preference		Interpreter Needed: <input type="checkbox"/>	
Written Language Preference		Translation Needed: <input type="checkbox"/>	
Indicate if the family currently has AFC in the family home.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		

Is the Individual DDS Eligible?	<input type="checkbox"/> Adult <input type="checkbox"/> Child <input type="checkbox"/> ASD Only
DDS Area Office:	
DDS Service Coordinator:	
Family Support Center/Program:	
Family Support Staff Person:	

Family Composition, Strengths and Needs

Information and Assistance Requested by Family

DDS Family Support Services	Agency	Status: Receiving or Needed	Start Date	Comments
<input type="checkbox"/> Family Support Center				
<input type="checkbox"/> Flexible Funding Allocation				
<input type="checkbox"/> IFFS				
<input type="checkbox"/> Medically Complex Program				
<input type="checkbox"/> Autism Support Center				
<input type="checkbox"/> SSQUAL Services (specify):				
<input type="checkbox"/> SSQUAL Services (specify):				
<input type="checkbox"/> Other (specify):				
<input type="checkbox"/> Other (specify):				

Areas of Focus for Service Navigation		
Focus Area:		
Action(s):	Person Responsible	Target Date
		Click here to enter a date
		Click here to enter a date
Status Update: <input type="checkbox"/> Completed <input type="checkbox"/> In Process <input type="checkbox"/> Unable to Complete	Date:	Click here to enter a date.
Comment:		

Focus Area:		
Action(s):	Person Responsible	Target Date
		Click here to enter a date
		Click here to enter a date
Status Update: <input type="checkbox"/> Completed <input type="checkbox"/> In Process <input type="checkbox"/> Unable to Complete	Date:	Click here to enter a date.
Comment:		

Focus Area:		
Action(s):	Person Responsible	Target Date
		Click here to enter a date
		Click here to enter a date
Status Update: <input type="checkbox"/> Completed <input type="checkbox"/> In Process <input type="checkbox"/> Unable to Complete	Date:	Click here to enter a date.
Comment:		

Additional Comments:

FAMILY SUPPORT PLAN SIGNATURE PAGE

Individual's Name:

Required Signatures Below:

Family Member/Guardian:		Date:	Click here to enter a date.
Individual (as appropriate):		Date	Click here to enter a date.

Family Support Staff Person:		Date:	Click here to enter a date.
Email:		Phone #:	

DDS Area Office Designee:		Date:	Click here to enter a date.
Email:		Phone #:	

☐ Service Coordinator has reviewed the Plan and placed the original copy in the individual's case file

SC Initials:

If this Plan is modified at a later date, please check box and indicate date.

<input type="checkbox"/> Plan Modification	Date Modified:	Click here to enter a date.
<input type="checkbox"/> Plan Modification	Date Modified:	Click here to enter a date.
<input type="checkbox"/> Plan Modification	Date Modified:	Click here to enter a date.
<input type="checkbox"/> Plan Modification	Date Modified:	Click here to enter a date.

ATTACHMENT F -- (SAMPLE)

ACTION PLAN

	Date Plan Developed: (M/D/YYYY)	
Individual's Name:		
DOB: (M/D/YYYY):	Click here to enter a date.	Age:
School, Job or Work/Day program		
Spoken Language Preference		Interpreter Needed: <input type="checkbox"/>
Written Language Preference		Translation Needed: <input type="checkbox"/>
Address:		

Caregiver Name & Relationship:			
Caregiver Address & Phone (if different):			
Telephone:			
Email:			
Spoken Language Preference		Interpreter Needed: <input type="checkbox"/>	
Written Language Preference		Translation Needed: <input type="checkbox"/>	
Indicate if the family currently has AFC in the family home.	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown		

Is the Individual DDS Eligible?	<input type="checkbox"/> Adult <input type="checkbox"/> Child <input type="checkbox"/> ASD Only		
DDS Area Office:			
DDS Service Coordinator:			
Family Support Center/Program:			
Family Support Staff Person:			

Information and Assistance Requested by Family

Areas of Focus for Service Navigation			
Focus Area:			
Action(s):	Person Responsible	Target Date	
		Click here to enter a date.	
		Click here to enter a date.	
Status Update: <input type="checkbox"/> Completed <input type="checkbox"/> In Process <input type="checkbox"/> Unable to Complete	Date:	Click here to enter a date.	
Comment:			

Focus Area:			
Action(s):	Person Responsible	Target Date	
		Click here to enter a date.	
		Click here to enter a date.	
Status Update: <input type="checkbox"/> Completed <input type="checkbox"/> In Process <input type="checkbox"/> Unable to Complete	Date:	Click here to enter a date.	
Comment:			

Family Support Inventory & Planning Tool

Guidelines for Gathering the Information You Need



Department of Developmental Services
January 2018

Purpose

This Family Support Inventory and Planning Tool (FSIPT) has been reformatted in 2018 and continues to serve as an information gathering tool for staff to use in working with families. This tool was redesigned in July 2013 by the DDS Future Planning Task Force Committee as part of the Department of Developmental Services strategic planning process around its delivery of family support services and supports. Family Support Centers and Programs are able to use this optional tool, or something similar, to assist them in supporting families.

Providers are welcome to modify and customize this Tool by adding local resources or other questions that may be relevant to the families with whom they work. It is anticipated this tool will primarily be used with families receiving Service Navigation assistance, either short-term or extended. All planning with families should be family-centered with the intent of building upon existing strengths and capacities. With that in mind, this Tool should be implemented in a flexible, family-friendly way, and can be used by section and/or completed incrementally over time, depending on what will be most responsive to the needs of the family.

This is not intended to be an exhaustive list, but does attempt to provide a comprehensive listing of varied types of resources and supports.

Additionally this Tool is intended to:

- Identify assistance or information families are seeking;
- Be a helpful planning tool and inform goals/areas of focus for Service Navigation; and
- Provide information to Family Support Centers/Programs regarding common training needs and interests among families.

Staff Person Completing This Form:	
Agency:	
Agency:	
Primary Phone:	
Email:	
Date:	Click here to enter a date.
Revised Date:	Click here to enter a date.
Revised Date:	Click here to enter a date.
Revised Date:	Click here to enter a date.

FAMILY SUPPORT INVENTORY AND PLANNING TOOL

1. Individual/Family Information

Individual's Name:		DOB:	Click here to enter a date.	Age:	
Address:					
Primary Phone:		Secondary Phone:			
Email:					

Individual's School or Job/Work/Day Program

Parent/Caregiver Name and Address					
Primary Phone:		Secondary Phone:			
Email:					

Parent/Caregiver Name and Address					
Primary Phone:		Secondary Phone:			
Email:					

Legal Guardian(s)/Caregiver(s) Name(s) and Address(s)					
Primary Phone:		Secondary Phone:			
Email:					

(1) Emergency Contact Name and Address					
Primary Phone:		Secondary Phone:			
Email:					
Secondary Email:					

(2) Emergency Contact Name and Address					
Primary Phone:		Secondary Phone:			
Email:					
Secondary Email:					

Spoken Language Preferred by Family		Interpreter Needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Written Language Preferred by Family		Translation Needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Spoken Language Preferred by Person		Interpreter Needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Written Language Preferred by Person		Translation Needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>

2. Eligibility

Is the individual eligible as an adult or child?	<input type="checkbox"/> No <input type="checkbox"/> Yes ➔ If yes, <input type="checkbox"/> Child <input type="checkbox"/> Adult
--	--

DDS Area Office and DDS Service Coordinator:

3. Support Needs

What are your family member's current diagnoses?

Describe your family member's strengths and interests:

What are the highest priority needs for your family member? In what areas do they need more support?

Does the individual have specific support needs in any of the following areas? (Check all that apply)			
<input type="checkbox"/> Medical	<input type="checkbox"/> Behavioral	<input type="checkbox"/> Communication	<input type="checkbox"/> Mental Health
<input type="checkbox"/> Mobility	<input type="checkbox"/> Vision	<input type="checkbox"/> Hearing	<input type="checkbox"/> Other
Please Specify:			

4. Caregiver Information

Number of primary caregivers in the home	
Primary caregiver(s) relationship	
Are any primary caregiver(s) under age 21?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Are any primary caregiver(s) over 65?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Are any primary caregiver(s) grandparents?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Number and relationship of other family members needing care	
Number of children under 10 years of age	
Is caregiver eligible for DDS, DMH or other support agency?	Yes <input type="checkbox"/> No <input type="checkbox"/> If Yes, Write Below

Are there any special concerns/stressors faced by the family?	Yes <input type="checkbox"/> No <input type="checkbox"/> If Yes, Write Below

Family Living Situation:		
<input type="checkbox"/> Owns own home	<input type="checkbox"/> Rents Home	<input type="checkbox"/> Lives in Subsidized Housing
<input type="checkbox"/> Lives in Shelter	<input type="checkbox"/> Homeless	<input type="checkbox"/> Other

Military Status:				
<input type="checkbox"/> Caregiver	Branch?		<input type="checkbox"/> Active Duty	<input type="checkbox"/> Veteran
<input type="checkbox"/> Individual	Branch?		<input type="checkbox"/> Active Duty	<input type="checkbox"/> Veteran
Comments:				

5. Vision of the Future

What is the life vision of the individual? What does s/he want her/his life to look like in five years? In ten or twenty?

What life vision does the family have for the individual?

What is the life vision for the family and siblings in caring for the individual?

6. Potential or Current Resources Available to Individual and Family

Please indicate resources the individual/family currently receives or Follow-up Needed				
Day Services	Receiving	Frequency	Follow-Up	Comments
Adult Day Health	<input type="checkbox"/>		<input type="checkbox"/>	
Clubhouse	<input type="checkbox"/>		<input type="checkbox"/>	
Community Based Day Supports/CBDS	<input type="checkbox"/>		<input type="checkbox"/>	
Competitive Employment	<input type="checkbox"/>		<input type="checkbox"/>	
Day Habilitation	<input type="checkbox"/>		<input type="checkbox"/>	
Employment Training	<input type="checkbox"/>		<input type="checkbox"/>	
Supported Employment	<input type="checkbox"/>		<input type="checkbox"/>	
Other Day Supports	<input type="checkbox"/>		<input type="checkbox"/>	
Rehabilitation Services	Receiving	Frequency	Follow-Up	Comments
Block Nursing	<input type="checkbox"/>		<input type="checkbox"/>	
Community Case Management	<input type="checkbox"/>		<input type="checkbox"/>	
Early Intervention	<input type="checkbox"/>		<input type="checkbox"/>	
Home Health Aide	<input type="checkbox"/>		<input type="checkbox"/>	
Mental Health/Counseling Services	<input type="checkbox"/>		<input type="checkbox"/>	
Occupational Therapy	<input type="checkbox"/>		<input type="checkbox"/>	
Physical Therapy	<input type="checkbox"/>		<input type="checkbox"/>	
Speech Therapy	<input type="checkbox"/>		<input type="checkbox"/>	
Visiting Nurses	<input type="checkbox"/>		<input type="checkbox"/>	
Financial/Reimbursements/Voucher	Receiving	Frequency	Follow-Up	Comments
Adult Foster/Family Care (AFC)	<input type="checkbox"/>		<input type="checkbox"/>	
DDS Flexible Funding Allocation	<input type="checkbox"/>		<input type="checkbox"/>	
Energy Assistance (heat, electricity, etc)	<input type="checkbox"/>		<input type="checkbox"/>	
Food Stamps (SNAP)	<input type="checkbox"/>		<input type="checkbox"/>	
Housing Subsidy	<input type="checkbox"/>		<input type="checkbox"/>	
Personal Care Assistant (PCA)	<input type="checkbox"/>		<input type="checkbox"/>	
SSI/SSDI	<input type="checkbox"/>		<input type="checkbox"/>	
Women, Infants and Children (WIC)	<input type="checkbox"/>		<input type="checkbox"/>	
Children Services	Receiving	Frequency	Follow-Up	Comments
ARICA Services	<input type="checkbox"/>		<input type="checkbox"/>	
Children's Autism Waiver Program	<input type="checkbox"/>		<input type="checkbox"/>	
Children's Behavioral Health Initiative	<input type="checkbox"/>		<input type="checkbox"/>	
DESE/DDS Program	<input type="checkbox"/>		<input type="checkbox"/>	
Intensive Flexible Family Support -IFFS	<input type="checkbox"/>		<input type="checkbox"/>	
Medically Complex Program	<input type="checkbox"/>		<input type="checkbox"/>	

Medical Insurance/Reimbursement	Receiving	Frequency	Follow-Up	Comments
Catastrophic Illness in Children Relief Fund	<input type="checkbox"/>		<input type="checkbox"/>	
CommonHealth	<input type="checkbox"/>		<input type="checkbox"/>	
Durable Medical Equipment (DME)	<input type="checkbox"/>		<input type="checkbox"/>	
Kaileigh Mulligan Program	<input type="checkbox"/>		<input type="checkbox"/>	
MassHealth/Medicaid	<input type="checkbox"/>		<input type="checkbox"/>	
Premium Assistance Program	<input type="checkbox"/>		<input type="checkbox"/>	
Private Health Insurance	<input type="checkbox"/>			
(Insurer Name):				
Resource Centers	Receiving	Frequency	Follow-Up	Comments
Autism Support Centers (DDS)	<input type="checkbox"/>		<input type="checkbox"/>	
Elder Service Agencies (ASAPs)	<input type="checkbox"/>		<input type="checkbox"/>	
Family Resource Centers (DCF)	<input type="checkbox"/>		<input type="checkbox"/>	
Independent Living Centers (ILC)	<input type="checkbox"/>		<input type="checkbox"/>	
Other:				

7. Community Connections/Supports: Affiliations and Opportunities

Community Connections/Supports	Receiving	Frequency	Follow-Up	Comments
Clubs	<input type="checkbox"/>		<input type="checkbox"/>	
Ethnic Associations	<input type="checkbox"/>		<input type="checkbox"/>	
Religious/Faith Based Communities	<input type="checkbox"/>		<input type="checkbox"/>	
Service Organizations	<input type="checkbox"/>		<input type="checkbox"/>	
Sports, Health and Fitness Org.	<input type="checkbox"/>		<input type="checkbox"/>	
Support Groups	<input type="checkbox"/>		<input type="checkbox"/>	
Town Recreation Programs	<input type="checkbox"/>		<input type="checkbox"/>	
Volunteer Organizations	<input type="checkbox"/>		<input type="checkbox"/>	
Other:				
Comments:				

8. Individual/Family Identified Informational or Planning Needs

Topical Area	Receiving	Follow-Up	Comments
Adaptive Equipment	<input type="checkbox"/>	<input type="checkbox"/>	
Alternative Augmentative Communication (AAC)	<input type="checkbox"/>	<input type="checkbox"/>	
Assistive Technology	<input type="checkbox"/>	<input type="checkbox"/>	
Autism Information/Resources	<input type="checkbox"/>	<input type="checkbox"/>	
Behavioral Supports/Consultation	<input type="checkbox"/>	<input type="checkbox"/>	
Child Care/After School	<input type="checkbox"/>	<input type="checkbox"/>	
Educational Support	<input type="checkbox"/>	<input type="checkbox"/>	
Elder Services	<input type="checkbox"/>	<input type="checkbox"/>	
Emergency Planning (9-1-1 Indicator Form)	<input type="checkbox"/>	<input type="checkbox"/>	
Employment	<input type="checkbox"/>	<input type="checkbox"/>	
Estate Planning	<input type="checkbox"/>	<input type="checkbox"/>	
Family Leadership	<input type="checkbox"/>	<input type="checkbox"/>	
Financial Planning	<input type="checkbox"/>	<input type="checkbox"/>	
Financial Support	<input type="checkbox"/>	<input type="checkbox"/>	
Guardianship/Other Options	<input type="checkbox"/>	<input type="checkbox"/>	
Home Modifications	<input type="checkbox"/>	<input type="checkbox"/>	
Housing Options	<input type="checkbox"/>	<input type="checkbox"/>	
Immigration Related Assistance	<input type="checkbox"/>	<input type="checkbox"/>	
Legal Resources	<input type="checkbox"/>	<input type="checkbox"/>	
Medical/Health Care	<input type="checkbox"/>	<input type="checkbox"/>	
Nutritional Information	<input type="checkbox"/>	<input type="checkbox"/>	
Parenting Skills/Support	<input type="checkbox"/>	<input type="checkbox"/>	
Person Centered Planning	<input type="checkbox"/>	<input type="checkbox"/>	
Recreational/Social Opportunities	<input type="checkbox"/>	<input type="checkbox"/>	
Respite	<input type="checkbox"/>	<input type="checkbox"/>	
Self-advocacy	<input type="checkbox"/>	<input type="checkbox"/>	
Self-Directed Service Options	<input type="checkbox"/>	<input type="checkbox"/>	
Sibling Supports	<input type="checkbox"/>	<input type="checkbox"/>	
Transition Planning	<input type="checkbox"/>	<input type="checkbox"/>	
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	
Vacation/Camp Programs	<input type="checkbox"/>	<input type="checkbox"/>	
Vehicle/Home Modifications	<input type="checkbox"/>	<input type="checkbox"/>	
Other:			

9. Other State Agency Services

Indicate if individual/family is presently receiving services from any of the state agencies listed below or could be eligible for these services. The intent is to help maximize resources available to families and to facilitate coordination of services.

Other State Agency Services	Receiving	Follow-Up	Contact	Telephone
Department of Children and Families(DCF)	<input type="checkbox"/>	<input type="checkbox"/>		
Department of Mental Health(DMH)	<input type="checkbox"/>	<input type="checkbox"/>		
Department of Public Health(DPH)	<input type="checkbox"/>	<input type="checkbox"/>		
Department of Transitional Assistance(DTA)	<input type="checkbox"/>	<input type="checkbox"/>		
Department of Youth Services(DYS)	<input type="checkbox"/>	<input type="checkbox"/>		
Executive Office of Elder Affairs (EOEA)	<input type="checkbox"/>	<input type="checkbox"/>		
MA Commission for the Blind(MCB)	<input type="checkbox"/>	<input type="checkbox"/>		
MA Rehabilitation Commission(MRC)	<input type="checkbox"/>	<input type="checkbox"/>		
MA Comm. for the Deaf & Hard of Hearing	<input type="checkbox"/>	<input type="checkbox"/>		
(SHIP)- Statewide Head Injury Program	<input type="checkbox"/>	<input type="checkbox"/>		
Other:				
Comments:				

10. Educational Plan/Placement

Educational Plan/Placement	Receiving	Follow-Up
Is the individual currently enrolled in a school program?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
If yes, does the individual have an IEP?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
Is the current IEP signed and accepted by the family?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
Does the individual have a 504 plan?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
Does individual currently participate in DESE/DDS program?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
Has Chapter 688 referral been made?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
688 Referral Received by DDS?	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="checkbox"/>
Expected Graduation Date on IEP:	Yes <input type="checkbox"/> No <input type="checkbox"/>	
School Placement	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Does the educational program include?	<input type="checkbox"/> In-Home Supports	
<input type="checkbox"/> Extended Day	<input type="checkbox"/> Extended Year	<input type="checkbox"/> Transition Planning Form
<input type="checkbox"/> Transportation		
School Contact Information		
Contact Name:		
Contacts Primary Phone Number:		
Email:		
Contacts Secondary Phone Number:		
Email:		
Briefly describe any concerns:		

Follow-Up with DDS	Follow-Up	Comments
Adult/Child Eligibility	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Autism Support Centers	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Family Leadership	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Family Support Center: <ul style="list-style-type: none"> Extended Service Navigation Flexible Funding Allocation 	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>	
Intensive Flexible Family Supports (IFFS)	Yes <input type="checkbox"/> No <input type="checkbox"/>	
Medically Complex Program	Yes <input type="checkbox"/> No <input type="checkbox"/>	
SSQUAL/In Home and Community Supports: <ul style="list-style-type: none"> Adult Companion Behavioral Supports and Consultation In-Home Supports Respite Other: Other: Other: Other: 	 Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>	

Provide Resource Information about other Advocacy Groups or Family Organizations

Resource Information	Send Info to Family	Comments
Alzheimer's Association	<input type="checkbox"/> Yes	
AANE (Asperger/Autism Network)	<input type="checkbox"/> Yes	
Arc Massachusetts	<input type="checkbox"/> Yes	
➤ Local Arc Chapter	<input type="checkbox"/> Yes	
Advocates for Autism of MA (AFAM) - Autism	<input type="checkbox"/> Yes	
BIA-MA (Brain Injury Association of MA)	<input type="checkbox"/> Yes	
Family TIES	<input type="checkbox"/> Yes	
Federation for Children with Special Needs	<input type="checkbox"/> Yes	
MASS- Massachusetts Advocates Standing Strong	<input type="checkbox"/> Yes	
MDSC- Down Syndrome Congress	<input type="checkbox"/> Yes	
MSSN- MA Sibling Support Network	<input type="checkbox"/> Yes	
MFOFC- Massachusetts Families Organizing for Change	<input type="checkbox"/> Yes	
PAL- Parent Advocacy League	<input type="checkbox"/> Yes	
Other:		

Additional Follow-Up Activities

Family Support Data Reporting Process

Family Support Centers Semi-Annual Reports

Who Completes?	All Family Support and Cultural/Linguistic Family Support Centers
When is the report due?	Semi-Annually: after first six months and end of fiscal year
Who receives the report?	Area Director(AD) and Regional Family Support Director(RFSD)
Who forwards it on and to whom?	RFSD completes Regional Report and sends to Statewide FS Director
Is there a Statewide report generated?	Yes, Statewide Family Support Center Report

Intensive Flexible Family Support Programs Annual Report

Who Completes?	All IFFS Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	AD and RFSD both receive Area IFFS Reports; RFSD receives Regional IFFS Reports directly
Who forwards it on and to whom?	RFSD reviews Annual IFFS Reports and completes summary data sheet on all the IFFS programs in region; forwards them to Statewide Director of Family Support
Is there a Statewide report generated?	Yes, Statewide IFFS Summary

Medically Complex Programs Annual Report

Who Completes?	All Medically Complex Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	Regional Family Support Director(RFSD)
Who forwards it on and to whom?	RFSD reviews Annual Report(s) and forwards to Statewide Director of Family Support
Is there a Statewide report generated?	Yes, Statewide Medically Complex Programs Summary

Family Leadership Programs Annual Report

Who Completes?	All Family Leadership Programs
When is the report due?	Annually: end of fiscal year
Who receives the report?	Regional Family Support Director (RFSD)
Who forwards it on and to whom?	RFSD reviews Annual Report(s) and forwards to Statewide Director of Family Support
Is there a Statewide report generated?	Not at this time. DDS holds Statewide meeting of all Family Leadership Programs to review the year and set new goals.

Autism Support Centers Semi-Annual Report

Who Completes?	All Autism Support Centers
When is the report due?	Semi-Annually: after first six months and end of fiscal year
Who receives the report?	Assistant Commissioner of Policy, Planning and Children's Services and Regional Family Support Directors and Regional Autism Coordinators receive all reports.
Who forwards it on and to whom?	Regional Family Support Directors should forward reports for centers in their respective regions to Statewide Director of Family Support.
Is there a Statewide report generated?	Not at this time.

Family Support Centers Semi-Annual Data Report -- (SAMPLE)

Family Support Center:		Semi-Annual Report 1: (7/1 – 12/31)	<input type="checkbox"/>
Person Completing Data Report:		Semi-Annual Report 2: (1/1 – 6/30)	<input type="checkbox"/>
Email Address:			
Phone Number:		TOTAL Number FTE's, based on monthly accommodation rate:	
Annual Funding Level for Family Support Center (based on number of FTEs):		If any of the FTE's above are identified for a specific purpose/activity, please specify both the FTE and purpose Ex: Social/Rec Coordination, 1 FTE	
		Date of Report:	Click here to enter a date.

1. Short-Term Service Navigation

Provide the total number of children and adults who received Short-Term Service Navigation during the reporting period.

At the end of the fiscal year, provide an unduplicated count of the total number of different children and adults who received Short-term Navigation (each child/adult is only counted once).

Short-Term Service Navigation	Report 1	Report 2		At end of fiscal year, provide an <u>unduplicated</u> total #
Number of Children				
Number of Adults				
Total:				
Comments:				

2. Extended Service Navigation

Provide the total number of children and adults who received Extended Service Navigation during the reporting period.

At the end of the fiscal year, provide an unduplicated count of the total number of different children and adults who received Extended Navigation (each child/adult is only counted once).

Extended Service Navigation	Report 1	Report 2		At end of fiscal year, provide an <u>unduplicated</u> total #
Number of Children				
Number of Adults				
Total:				
Comments:				

3. Administration of Flexible Funding Allocations

Provide the total number of children and adults who received a flexible funding payment this reporting period and the total amount of funding that was distributed. Each child and adult should only be counted once in each reporting period.

At the end of the fiscal year, provide an unduplicated count of the total number of different children and adults who received a Flexible Funding payment.

Flexible Funding Payment	Report 1	Report 2		At end of fiscal year, provide an <u>unduplicated</u> total #
Number of Children				
Number of Adults				
Total Number				
Total Amount of Funding				
Comments:				

4. Small Group Activities (this includes: parent and sibling support groups; self-advocacy groups; skill-building classes, etc.) sponsored by the Center:

Small Group Activities	Report 1	Report 2		At end of fiscal year, provide an <u>unduplicated</u> total #
Total Number of Small Group Activities				
Total Number of Participants				
Comments:				

Provide Description of Small Group Activities on Table A.

5. Training/Educational Events for Individuals/Families Provided by the Center:

Training/Educational Events	Report 1	Report 2		Annual Total* (at end of fiscal year)
Number of Trainings				
Total Number of Participants				
Comments:				

* These numbers may be a duplicated count if individuals/families attend more than one event

Provide Description of Trainings/Educational Events on Table B

6. Special Events (social, recreational, family, and community events) sponsored by the Center*

Social/Family/Community Events	Report 1	Report 2		Annual Total* (at end of fiscal year)
Number of Events				
Total Number of Participants				
Comments:				

* These numbers may be a duplicated count if individuals/families attend more than one event

Provide Description of Special Events on Table C

Table A. Small Group Activities/Support Groups

Type of Group	Designed for Adults with ASD Only	Location	Frequency (weekly/ monthly)	Duration (# weeks/ months)	# Of Participants
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				

Table B. Training/Educational Events

Date	Topic	Designed for Adults with ASD Only	Location	# of Participants
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		
		<input type="checkbox"/>		

Table C. Special Events Sponsored or Facilitated by the Center

Date	Activity	Designed for Adults with ASD Only	Location	1-Time Y/N	Recurring Y/N	Frequency (ex. weekly/ monthly)	# of Participants	Additional Funding Resources Used Y/N
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						
		<input type="checkbox"/>						

Year End Summary/Annual Report

1. **Provide the total for the fiscal year: short-term or extended service navigation; flexible funding; or participation in small group/support group activities. number of different individuals (children and adults) who received one of the following services during**

Please Note: This should be an <u>unduplicated</u> total which means each individual is <u>counted only once even if they received or participated in more</u> than one of these services during the fiscal year. This number should also include the total number of ASD individuals referenced in Question 3.	
Overall Total Number:	
Of this Overall Total Number Served, number of families who are new this year:	

2. **Number of individuals with ASD over age 18 and/or their families you have assisted:**

This represents the expansion population of adults (over age 18) with an Autism Spectrum Disorder (ASD) who do not have Intellectual Disability. Services include any of the following: short-term or extended service navigation; flexible funding; participation in small group skill building, social, or support group activities.	
--	--

3. **Supports for Individuals with ASD over age 18 and their families:**

What are the specific services or supports that your Center offers for individuals with ASD over age 18 and their families? What strategies or services have been successful in reaching and supporting these individuals and/or their families?

4. **Information Dissemination**

Describe the different dissemination approaches used by the Center to provide information to families. This may include newsletters, email distribution lists, list-serves, webinars, etc. Please include the frequency of communication for each approach used and the total number of people who receive this information. (For example, a newsletter is sent out quarterly to 300 people on the Center mailing list).
Include information about the Center's use of a web-site and other forms of social media to share information (i.e. Facebook, etc.).

5. Outreach Activities

a. Describe specific outreach activities initiated by the Center with other organizations/entities to help reach individuals/families who may be eligible for DDS services and to share information about Center activities and resources. (Examples may include: early intervention programs; Community health centers; local schools)
b. Describe any specific cultural diversity outreach and service activities. What has been initiated to outreach and engage individuals and families from different cultural and linguistic groups?

6. Community Connections and Partnerships

a. What organizations or individuals have been contacted to explore the possibility of collaborative efforts?
b. Describe any existing and/or new community linkages and collaborative activities that have been established.
c. Has the Center been able to access grants or other funding resources to support or expand Center activities?
If yes, please provide information about how this funding has been used to support different Center activities or initiatives

7. Individual/ Family Satisfaction

a. How have you assessed individual/family feedback regarding Center services and activities this past year?
b. What changes (if any) are you planning to make to the Center's services, activities and program operation based on the feedback you have received?

Please feel free to provide any other information of interest that occurred during this year.

Family Support Center Data Reporting: Information and Guidance FY "18"

Introduction:

The Department has updated the data reports the Family Support and Cultural/Linguistic- Specific Centers are required to complete, including this corresponding Information and Guidance. These changes have been made based on the experience and feedback from providers, families and DDS staff. These changes are designed to streamline the reporting process, with a focus on collecting the most important types of information needed to provide a good understanding of the utilization of the different services offered by the Centers, and the number of individuals/families who benefit from these services.

Key Elements include:

- The data collection continues to require **semi-annual reports**, with a **Year End Summary/Annual Report**. The semi-annual reports cover the periods of: 7/1-12/31, and 1/1-6/30.
- The data collection report is designed to more clearly capture 3 important types of information/data:
 - ◆ The **volume/level of activity** for each service at the end of each 6 month period by collecting information on the number of all individuals participating in specific services.
 - ◆ Obtaining a **non-duplicated count** of individuals who participated in specific services across the year, to provide the total number of **different individuals** who received specific services.
 - ◆ A **total number of individuals, non-duplicated**, who participated in these specific Center services across the year: Short-Term Service Navigation; Extended Service Navigation; Small Group Activities; and Flexible Funding Allocations.

Guidance for Completing Data Reports:

When completing these reports, children are defined as under age 18, and adults are age 18 and over. There are instructions on the data report, and this guidance is offered to provide some supplemental information and examples.

DDS Annual Funding Level for FS Center: Provide the annual amount of DDS funding for the actual operation of the Center, based on the size of the Center as determined by the number of associated full-time equivalent staff (FTEs). This is the accommodation rate for the Center (program code 3770). Do not include Flexible Funding Allocations (program code 3779) in this amount. **NOTE: The DDS funding amount should match the accommodation rate regardless when the FTE was added during the fiscal year.**

Questions 1 and 2: Short-Term and Extended Service Navigation

- **Please refer to the attached Guidance for the definitions of Short-Term and Extended Navigation.**
- Record the number of children and adults whose families/caregivers received these services during each of the 6 month reporting periods.
- If individuals received these services in both reporting periods, they should be included in both of the 6 month reporting totals.
- **At the end of the fiscal year however, if individuals received services across both reporting periods they should only be counted once.** The purpose of requesting a **non-duplicated** count at the end of the fiscal year is to be able to report the total number of different children and adults who received this service.

Question 3: Administration of Flexible Funding Allocations

- Record the number of children and adults whose families/caregivers received a flexible funding allocation during each of the 6 month reporting periods.
- Provide the total amount of funding that was distributed to individuals during the 6 month reporting period.
- **Please Note: each child/adult should only be counted once in a reporting period.** Example, if an individual is getting an \$ 800.00 allocation that is distributed in two payments of \$400.00 each and it occurs in the same 6 month period, the individual only gets counted once. However, if the allocation occurs over the two reporting periods, then the funding amount would be \$400.00 for each reporting period and the individual would be counted in each report.
- At the end of the fiscal year: provide a **non-duplicated count** of individuals who received a flexible funding allocation, which will report the total number of different children and adults who received this service; and provide the total amount of funding that was distributed across the fiscal year.

- **Question 4: Small Group Activities** This includes parent/sibling support groups, self-advocacy groups, and skill-building classes that meet multiple times, with at least a minimum of 2 to 3 times, but may occur at different frequencies (weekly, monthly) and over different periods of duration- across the year, over a 3 month period, etc.
- Record the total number of group activities sponsored by the Center each reporting period.
- Report the total number of individuals who participated in these support groups/small groups activities each period. This number should represent the highest number of people who participated in each of the support/small groups, totaled across all of the activities, and not a duplicative count of individuals each time they attended a session. Example: If a parent support group that meets monthly has up to 15 parents who attend this meeting, the total number of participants would be reported as 15 (and not 90, 15 members times 6 meetings). If the number of participants varies from one meeting to the next, go with the highest number of participants at one of the group activities.
- At the end of the fiscal year, provide a non-duplicated summary of groups sponsored, and a non-duplicated count of participants.
- Complete information about the types of small groups offered on **Table A**. The text on each line will wrap and more rows can be added to the table if additional space is needed.
- **Frequency** refers to how often the group meets, and **duration** refers to the overall period of time the group is offered. Examples: A social skills class that meets weekly for 3 months: frequency is weekly and duration is 3 months; A support group that meets monthly and is offered on an ongoing basis: frequency is monthly and duration is ongoing.

Question 5: Training/Educational Events

- Record the total number of training/educational events sponsored by the Center each reporting period.
- Report the total number of individuals who participated in these training/educational events each period. Individuals should be counted for every event they attended, which means some individuals who attended more than one training will be counted more than once, which is fine. It is recognized that this total may be a duplicated count.
- Complete information about the types of training/educational events offered on **Table B**. The text on each line will wrap and more rows can be added to the table if additional space is needed.

Question 6: Special Events- This includes social, recreational, family and community events sponsored or facilitated by the Center.

- Record the total number of special events sponsored by the Center each reporting period.
- Record the total number of individuals who participated in these special events each period. All individuals who participate should be counted for every event they attend.
- Complete information about the types of special events offered on **Table C**. The text on each line will wrap and more rows can be added to the table if additional space is needed. Indicate with a yes or no, whether it is a one-time event or recurring, and if recurring, indicate the frequency.

- Sometimes these special events are made available through the use of additional funding the Center has obtained through grants or other resources. Please indicate with a yes or no whether additional funding was used to support a specific event.

Year-End Summary/Annual Report: This report is intended to supplement the semi-annual reports and provides an opportunity to highlight other Center services, activities, initiatives and accomplishments.

Question 1: This is intended to capture a **non-duplicated count** of individuals who received and/or participated in any one of the following services at any time during the fiscal: 1) Short-Term Service Navigation; 2) Extended Service Navigation; 3) Flexible Funding Allocations; 4) Small Group/Support Group Activities. It is very important to the Department to have a **reliable total count of different individuals (non-duplicated) who have participated in and benefitted from these direct services to families.**

Question 2: This question represents the expansion population of adults (over age 18) with an Autism Spectrum Disorder (ASD) who do not have an Intellectual Disability. Services include any of the following: short-term or extended service navigation; flexible funding; participation in small group skill building, social, or support group activities.

Questions 3 to 6: Provide information to the questions posed and offer any other relevant information that you think captures and reflects the services and initiatives provided by the Center this fiscal year.

Family Support Centers Definitions for Levels of Support

**Information and Referral ~
Short-Term Service Navigation ~ Extended Service Navigation**

Information and Referral

Information and Referral, (I & R) is defined as a service that provides direction and consultation and is usually concluded in one session. Any family is welcomed to call over the course of a year for information on any variety of subjects. An I&R service can be defined as (but not limited to) a face to face meeting, a phone call, information mailed to a family. Families who utilize I & R are able to respond independently upon receiving the requested information. Examples of I & R include but are not limited to the following:

- A Center received a call looking for information on the SNAP program. Staff shared the information about the program and provided the phone number and website information. The family was able to take the information provided and complete their task independently.
- The parent of an adult who has a suspected intellectual disability walks into a Center and asks if they can get their son eligible for services. Staff provides some general information on the eligibility process and explains how to obtain further information. They shared the phone number to the Area Office and the web site with instructions on how to download an application. The family was able to proceed with no further assistance.
- A family who is eligible and receives services from a Center calls looking for information about guardianship. Center staff informs them of an upcoming training on that topic. The staff person shares the date, time and location of the training. The family attended and proceeded with guardianship independently.
- A person calls the Center for information on a topic that requires some research. The staff person takes the name and number, looks into the matter and returns the call to the family. At that point the family is able to proceed on their own.
- I&R also includes newsletters, emails, resource sharing and trainings.

Service Navigation is designed to assist families in caring for their family member at home by providing individualized guidance, support and problem-solving assistance, as well as help families access and coordinate potential community resources and services. The assistance provided to families is varied and dependent on each family circumstance. There are two levels of support; Short-Term Service Navigation and Extended Service Navigation. The definitions and examples below are an attempt to assist the Family Support Centers and DDS staff to understand the differences in the two levels of support. There will always be situations that do not “fit” easily into either category. In those instances, discussion between the Area Office and the Family Support Center will aid in deciding what level of support to use. Families can move between Short-Term Service Navigation and Extended Service Navigation as deemed necessary by the Area Office.

Short-Term Service Navigation

Short-Term Service Navigation is designed to assist an individual or a family with matters they are not able to resolve alone. Short-Term Navigation is anticipated to be:

- Short in duration (Can range from 1 week up to 6 months)
- OR
- Very low intensity over a longer period of time (10 – 30 minutes per month for 6 months +)

Examples of Short-Term Service Navigation include but are not limited to the following:

- A family is in need of assistance with filling out many applications including Public housing, SNAP (food stamps), T pass for the disabled and SSI. Center staff sits with the family and assists in filling out all applications and walks them through the initial meeting with the housing authority. This case would be high intensity due to the time the staff invests in the application and meeting process, but is short in duration.
- Families, who are members of the Center, are bilingual and require regular assistance on a monthly basis to read their mail to assure they have not missed important information. Staff may spend up to 30 minutes per session, but only one time per month. There is no need for communication during the month or for follow up on any matters so it is low intensity.
- A family is in turmoil because the child is being suspended from school. They have not received services from the Center before so are not known to them. The Center assists the family in discussion with the school, determining how long he will be suspended and what needs to happen to possibly prevent it. This is high intensity but short term navigation.

Extended Service Navigation

Extended Service Navigation is a CLOSED REFERRAL service that must be authorized from the Area Office. The Area can call the Center directly to enroll a family or the Center can contact the Area Office suggesting that a family be placed in Extended Service Navigation. Anyone in Extended Service Navigation must be recorded on the Monthly Service Delivery Report and have a Family Support Plan.

Extended Service Navigation is designed to provide long term support to a family who requires assistance and expertise in a variety of areas including regular communication and coordination of supports. It is anticipated there is a relationship built between this family and the Center in order to be responsive to family stressors as they arise. Examples of Extended Service Navigation can include but are not limited to:

- A single parent who has two children with intellectual disabilities. The parent struggles with mental health issues herself. Ongoing assistance is required for communication with the school, counseling services and reading and understanding all communication in writing from public housing. Due to the challenges this family faces there is always potential for the loss of housing, suspensions from school, challenging behaviors and hospitalization of the mother. The open and ongoing relationship with the Center can prevent or be immediately on top of any potential situations that may destabilize the family situation.
- A family requires assistance with a child who is newly DDS eligible. They need support and assistance with finding OT, PT and speech services and to coordinate with the school department as the child is behaviorally challenged and the risk of suspension is a constant reality. An ongoing and open relationship is necessary with this family to assure the Center is aware of all the potential family stressors that could cause additional challenges to this family.
- A family who is connected to a Center has an adult son with an intellectual disability. They live on the cusp of poverty, depending on the disability payment of the son and the disability payment of the mother who is disabled due to a previously broken back. There are general issues of cleanliness in the physical home, lack of consistent heat and/or electricity, and concerns about adequate nutrition. There have been two DPPC reports called in due to the condition of the home and the poor health of the adult son. The Center relationship with the family will assist in nutritional information for the family, assist with bill paying, assistance when and if the heating payments become lapsed in the colder months and any other issues that could arise and destabilize this family.

Autism Support Centers Semi-Annual Data Report -- (SAMPLE)

Autism Support Center:		Date of Report:	Click here to enter a date.
Person Completing Data Report:		Semi-Annual Report 1: (7/1 – 12/31)	<input type="checkbox"/>
Email Address:		Semi-Annual Report 2: (1/1 – 6/30)	<input type="checkbox"/>
DDS Annual Funding Level for Autism Support Center (based on number of FTEs):		TOTAL Number of FTE's, based on monthly accommodation rate:	
		From Total Above, Number of FTE's for General Center Activities:	
		From Total Above, Number of FTE's for Brokers/Waiver:	
		From Total Above, Number of FTEs for ASD Only:	

2. Information and Referral Services

Provide the total number of families of children, families of adults and individuals/professionals who contacted the Autism Support Center during the past fiscal year.			
Information & Referral Services	Report 1	Report 2	Annual Total (At End of Fiscal Year)
Number of Families of Children/Young Adult (Ages 0 yrs. – 22 yrs.)			
Total Number of Families of Adults (Ages 22 yrs. and up)			
Number of Professionals/Other			
Total:			
Comments:			

2. Small Group Activities

This includes: parent and sibling support groups; self-advocacy groups; skill- building classes, social/recreational activities, etc. that are sponsored by the Autism Support Center. Chart A is for activities that are intended for any individuals with ASD and/or their families. Chart B is to record activities specifically designed for individuals with ASD without ID. Activities should only be reported once, on either Chart A or Chart B.			
A. Small Group Activities Intended for <u>Any</u> Individuals with ASD and/or their Families			
	Report 1	Report 2	Unduplicated Total for Fiscal Year
Total Number of Small Group Activities			
Total Number of Participants			
Total Number of Participants - Age 0-5			
Total Number of Participants - Age 6-21			
Total Number of Participants - Age 22+			
Number of Family Members (parents, siblings, etc.)			
Comments:			

***Provide Description of Small Group Activities on Table A listed below.**

B. Small Group Activities Intended Primarily for Individuals with ASD <u>without</u> ID*			
	Report 1	Report 2	Unduplicated Total for Fiscal Year
Total Number of Small Group Activities			
Total Number of Participants			
Total Number of Participants – Age 14-21			
Total Number of Participants – Age 22+			
Number of Family Members (parents, siblings, etc.)			
Comments:			

3. Training/Educational Events

This includes: Trainings/Educational Events arranged or provided by the Autism Support Center.			
Training/Educational Events	Report 1	Report 2	Annual Total* (At End of Fiscal Year)
Total Number Trainings/Educational Events			
Total Number of Participants			
Comments:			

* These numbers may be a duplicated count if individuals/families attend more than one event

*Provide Description of Trainings/Educational Events on Table B listed below.

4. Special Events

This includes: Social, recreational, family, and community events that are sponsored by the Autism Support Center.			
Social/Family/Community Events	Report 1	Report 2	Annual Total* (At End of Fiscal Year)
Total Number of Events			
Total Number of Participants			
Comments:			

* These numbers may be a duplicated count if individuals/families attend more than one event

*Provide Description of Special Events on Table C listed below.

Table A. Small Group Activities/Support Groups

Only check the second column if the trainings/educational events are specifically designed for and attended by individuals w/o an intellectual disability and/or their families.					
Type of Group	Designed for Adults with ASD Only	Location	Frequency (weekly/monthly)	Duration (# weeks/months)	# Of Participants
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				
	<input type="checkbox"/>				

Table B. Training/Educational Events

Only check the second column if the trainings/educational events are specifically designed for and attended by individuals w/o an intellectual disability and/or their families.				
Date	Designed for Adults with ASD Only	Topic	Location	# of Participants
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			

Table C. Special Events Sponsored or Facilitated by the Center

Only check the second column if the Special Events are specifically designed for and attended by individuals w/o an intellectual disability and/or their families.								
Date	Designed for Adults with ASD Only	Activity	Location	1-Time Y/N	Recurring Y/N	Frequency (Weekly/Monthly)	# of Participants	Additional Funding Resources Used Y/N
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							
	<input type="checkbox"/>							

Year End Summary/Annual Report

1. Provide the total number of different individuals (children and adults) who received one of the following services during the fiscal year: participation in small group skill building, social or support group activities. Please Note: This should be an **unduplicated** total which means each individual is counted only once even if they received or participated in more than one of these services during the fiscal year. This number should also include the total number of ASD individuals referenced in number 2.

Overall Total Number:	
How many of these Families were new to the Center this year?	

2. Total Number of individuals with ASD over age 18 and/or their families you have assisted: This represents the expansion population of adults (over age 18) with an Autism Spectrum Disorder (ASD) who do not have Intellectual Disability. Services include any of the following: participation in small group skill building, social, or support group activities, etc.

Overall Total Number:	
Please note other ways you have supported these individuals and families.	

3. Information Dissemination
Describe the different dissemination approaches used by the Center to provide information to families. This may include newsletters, email distribution lists, list-serves, webinars, etc. Please include the frequency of communication for each approach used and the total number of people who receive this information. (For example, a newsletter is sent out quarterly to 300 people on the Center mailing list).

Include information about the Center's use of a web-site and other forms of social media to share information (i.e. Facebook, etc.).	
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4. Outreach Activities

a) Describe specific outreach activities initiated by the Center with other organizations/entities to help reach individuals/families who may be eligible for DDS services and to share information about Center activities and resources. (Examples may include: early intervention programs; Community health centers; local schools)	
b) Describe any specific cultural diversity outreach and service activities. What has been initiated to outreach and engage individuals and families from different cultural and linguistic groups, especially people with limited English proficiency?	
c) What specific strategies and outreach activities have you used to reach individuals with autism w/o an intellectual disability and their families? What have been both the successful strategies and the challenges in engaging these newly eligible adults and their families?	
d) How does the Center outreach and support individuals and families who live in more rural areas, towns or cities further from the location of the Autism Support Center?	

5. Community Connections and Partnerships

a) What organizations or individuals have been contacted to explore the possibility of collaborative efforts?
b) Describe any existing and/or new community linkages and collaborative activities that have been established. Provide information about the nature of partnership, what services or programs are or will be offered, etc.
c) Has the Center been able to access grants or other funding resources to support or expand Center activities? If yes, please provide information about how this funding has been used to support different Center activities or initiatives

6. Individual/ Family Satisfaction

a) How have you assessed individual/family feedback regarding Center services and activities this past year?
b) What changes (if any) are you planning to make to the Center's services, activities and program operation based on the feedback you have received?

Please feel free to provide any other information of interest that occurred during this year.

Autism Support Center Data Reporting: Information and Guidance FY'19

Introduction:

The Department is initiating a new data report for the Autism Support Centers to complete, including this corresponding Information and Guidance. This report is designed specifically with a focus on collecting the most important types of information needed to provide a good understanding of the utilization of the different services offered by these Centers, and the number of individuals/families who benefit from these services.

Key Elements include:

- The data collection requires **semi-annual reports**, with a **Year End Summary/Annual Report**. The semi-annual reports cover the periods of: 7/1-12/31, and 1/1-6/30.
- The data collection report is designed to capture 3 important types of information/data:
 - ◆ The **volume/level of activity** for each service at the end of each 6 month period by collecting information on the number of all individuals participating in specific services.
 - ◆ Obtaining an **unduplicated count of individuals with ASD** with and without ID who participated in specific services across the year.
 - ◆ A **total number of individuals, unduplicated**, who participated in these specific Center services across the year: Small Group Activities and Training/Educational Events.

Guidance for Completing Data Reports:

When completing these reports, specific age groups are defined for each type of services. There are instructions on the data report, and this guidance is offered to provide some supplemental information and examples.

DDS Annual Funding Level for AS Center: Provide the annual amount of DDS funding for the actual operation of the Center, based on the size of the Center as determined by the number of associated full-time equivalent staff (FTEs). This is the accommodation rate for the Center (program code 3772), as established by the Chapter 257 rate setting. **NOTE: The DDS funding amount should match the accommodation rate regardless of when the FTE was added during the fiscal year.**

Total Number of FTEs: In completing these boxes, start with the total number of FTEs in the Autism Support Center **based on the monthly accommodation rate**. In the next three boxes below, identify **(from the total FTEs)** the number of FTEs available for general center activities; FTEs hired as autism waiver brokers and the FTEs assigned to work specifically with individuals with ASD only and their families.

Questions 1: Information and Referral Services

- Record the number of families/caregivers of individuals with ASD at the different age ranges who received I&R services in each reporting period as well as other professionals.
- If individuals received these services in both reporting periods, they should be included in both six month reporting periods.

Question 2: Small Group Activities

This includes parent/sibling support groups, self-advocacy groups, and skill-building classes that meet multiple times, with at least a minimum of 2 to 3 times, but may occur at different frequencies (weekly, monthly) and over different periods of duration- across the year, over a 3 month period, etc. Chart A is for activities that are intended for any individuals with ASD and/or their families. Chart B is to record activities specifically designed for individuals with ASD without ID. Activities should only be reported once, on either Chart A or Chart B. **Please follow these instructions for both Chart A and Chart B.**

- Record the total number of group activities sponsored by the Center each reporting period.
- Report the total number of these participants in these support groups/small groups activities each period. This number should represent the highest number of people who participated in each of the support/small groups, totaled across all of the activities, and not a duplicative count of individuals each time they attended a session. Example: If a parent support group that meets monthly has up to 15 parents who attend this meeting, the total number of participants would be reported as 15 (and not 90, 15 members times 6 meetings). If the number of participants varies from one meeting to the next, go with the highest number of participants at one of the group activities.
- At the end of the fiscal year, provide an unduplicated summary of groups sponsored, and a unduplicated count of participants.
- Complete information about the types of small groups offered on **Table A**. The text on each line will wrap and more rows can be added to the table if additional space is needed.
- **Frequency** refers to how often the group meets, and **duration** refers to the overall period of time the group is offered. Examples: A social skills class that meets weekly for 3 months: frequency is weekly and duration is 3 months; A support group that meets monthly and is offered on an ongoing basis: frequency is monthly and duration is ongoing.

Question 3: Training/Educational Events

- Record the total number of training/educational events sponsored by the Center in each reporting period.
- Report the total number of individuals who participated in these training/educational events for each period. Individuals should be counted for every event they attended. This means that some individuals who attended more than one training will be counted more than once, which is fine. It is recognized that this total may be a duplicated count.
- Complete information about the types of training/educational events offered on **Table B**. The text on each line will wrap and more rows can be added to the table if additional space is needed.

Question 6: Special Events - This includes social, recreational, family and community events sponsored or facilitated by the Center.

- Record the total number of special events sponsored by the Center each reporting period.
- Record the total number of individuals who participated in these special events each period. All individuals who participate should be counted for every event they attend.
- Complete information about the types of special events offered on **Table C**. The text on each line will wrap and more rows can be added to the table if additional space is needed. Indicate with a yes or no, whether it is a one-time event or recurring, and if recurring, indicate the frequency.
- Sometimes these special events are made available through the use of additional funding the Center has obtained through grants or other resources. Please indicate with a yes or no whether additional funding was used to support a specific event.

Year-End Summary/Annual Report: This report is completed at the end of the fiscal year when completing Report 2. It is intended to supplement the semi-annual reports and provides an opportunity to highlight other Center services, activities, initiatives and accomplishments.

Question 1: This is intended to capture an **unduplicated count** of individuals who received and/or participated in any Small Group/Support Group Activities/Social/Recreational Activities during the Fiscal Year. It is very important to the Department to have a **reliable total count of different individuals (unduplicated) who have participated in and benefitted from these direct services.**

Question 2: This question represents the expansion population of adults (over age 18) with an Autism Spectrum Disorder (ASD) who do not have an Intellectual Disability. Services include any of the following: participation in small group skill building, social, or support group activities.

Questions 3 and 4: Provide information to the questions posed and offer any other relevant information that you think captures and reflects the services and initiatives provided by the Autism Support Center this fiscal year.

Intensive Flexible Family Support Programs Annual Report -- (SAMPLE)

Program Name:		Region:	
Agency:		Person Completing Report:	
Fiscal Year: FY		Date of Report:	Click here to enter a date.

This report is intended to obtain both objective information about the number of individuals and families who benefitted from program services this past year, as well as qualitative information about overall experiences, trends, accomplishments and challenges.

A. Information on Program Participants

What is your program capacity based on your funding level?	
Provide the total number of individuals who received services this past fiscal year	
Of this number, how many had also received services during the previous fiscal year	
Provide the following information about individuals who received services this past fiscal year.	
Ages of Program Participants (Report age of the individual at the end of the fiscal year or at the time they left the program).	
Age 0-5	Ages 6 - 9
Ages 10 - 13	Ages 14 - 17
Ages 18 - 22	

Other demographic and related service information:

Characteristic	Number	Comments
Females		
Males		
Autism Spectrum Diagnosis		
Receiving services through ARICA		
Receiving CBHI services		
Receiving PCA services		
Receiving AFC services		
Involvement by DCF		
Single Parent Families		
Grandparents are primary caregivers		
Presence of extenuating health issues with parents/caregivers		
Families for whom English is not their first language		

1. Provide the following information about referrals:

a. Number of referrals to the Program this fiscal year	
B. Number of individuals referred but <u>not accepted</u> into the Program.	
Provide a brief description of the reasons for why referrals were not accepted.	
C. Is there a waiting list for Program participation?	<input type="checkbox"/> Yes <input type="checkbox"/> No
D. If yes, how many individuals are on the waiting list?	

5. Provide the following information about individuals who completed/were discharged from the IFFS program this past year.

Initials of Individual	Length of time in program	What services/programs were individuals connected to when leaving IFFS program	Comments

6. Provide any other descriptive/demographic information about the individuals/families actively receiving services to get a better understanding of the profiles of families and trends you may be seeing. For example, include information on the cultural/ethnic diversity of families, number of families for who English is not their first language, parents with cognitive limitations, etc...

B. Information on Flexible Funding:

1. Amount of Flexible funding that was allocated this fiscal year.	
2. Number of families who received flexible funding allocations.	
3. Provide a brief description of some of the common needs and uses of flexible funding allocations.	

C. Information on Generic and Non-DDS Resources Accessed on behalf of families:

One of the particular strengths of the IFFS Programs is the ability to identify and access other resources to help families meet their needs. This includes resources from both formal public and private entities, as well as informal and generic resources. Please provide the following information about non-DDS resources and funding you have successfully accessed or leveraged for families this past year.

For example, Citizens Energy - Joe-4-OIL.

Organization	Service	Purpose (s)	Comments

D. Community Partnerships/Collaboration: Provide a brief description of any partnerships or collaborative initiatives with other organizations developed this past year, if it has not already been noted above.

E. Successes: Describe any program highlights or specific successes/accomplishments achieved this past year, if not already noted elsewhere.

F. Challenges/Barriers: Provide information about some of the specific barriers families encounter in accessing or following through with services, and challenges you face in assisting families in getting the necessary services they require to support their family member at home.

G. Ideas/Needs for Future Development:

Feel free to provide any vignettes or quotes that help illustrate positive experiences and successful outcomes.

Medically Complex Programs Annual Report -- (SAMPLE)

Program Name:		Region:	
Agency:		Person Completing Report:	
Fiscal Year: FY		Date of Report:	Click here to enter a date.

This report is intended to obtain both objective information about the number of individuals and families who benefitted from program services this past year, as well as qualitative information about overall experiences, accomplishments and challenges.

A. Information on Program Participants:

1. Provide the total number of individuals who received comprehensive service navigation/case management services this past year.	
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2. Provide the following break-out by age range of the individuals who received services this past fiscal year. (report the age of the individual at the end of the fiscal year, or at the time they left the program, if that occurred during the year).			
Under Age 5		Ages Range 6 up to 10	
Ages Range 10 up to 14		Ages Range 14 up to 18	
Ages Range 18 up to 22		Ages Range 22 up to 25	

3. Provide the following information:	
a) Number of referrals to the Program this fiscal year.	
E. Number of individuals referred but not accepted into the Program.	
Provide a brief description of the reasons for why they were not accepted. (Below)	
F. Number of individuals who successfully completed/transitioned from the Program this past year.	
G. Is there a waiting list for Program participation?	<input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes , how many individuals are on the waiting list?	

4. Number of families who are part of the Program's broader Network/Coalition – (not receiving intensive service navigation/case management services, but part of your outer communication/support network)	
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Demographic Family Information

1. Please provide any other descriptive/demographic information about the families actively receiving services to get a better understanding of the profiles of families and trends you may be seeing. For example, include information on the cultural/ethnic diversity of families, number of families for whom English is not their first language, etc...	

4. Information on Flexible Funding Allocation:

1. Amount of Flexible funding that was allocated this fiscal year.	
2. Number of families who received flexible funding allocations.	
3. Provide a brief description of some of the common needs and uses of flexible funding allocations.	

B. Information on other funding resources accessed on behalf of families:

One of the particular strengths of the Medically Complex Programs is the ability to identify and access other funding resources to help families meet the needs of their family member with complex medical challenges. This includes resources from both formal public and private entities (such as the Catastrophic Illness Fund), as well as informal and generic resources. We would like you to provide the following information about the non-DDS funding you have successfully accessed or leveraged for families this past year.

Entity/ Source of Funding	Amount of Funding	Purpose (s)	Comments

C. Information on Services for Transition-Age Young Adults:

Provide information about the “transition-age program” services – how is this going; what have your experiences been assisting families of young adults with planning, identifying and accessing resources, and helping to developing post-school opportunities, including communication and working relationships with schools, Area Offices and other providers.

D. Community Partnerships/Collaboration:

Provide a brief description of any partnerships or collaborative initiatives with other organizations developed this past year, if it has not already been noted elsewhere.

E. Describe any outreach activities during the past year:

This includes strategies to develop parent-to-parent networks, newsletters, presentations, mailings, parent meetings, etc.

F. Communication with Families:

Given the geographic span of these Regional programs, how do you maintain communication with families? Do you have a system in place to ensure a certain level of contact with all families in a given year?

G. Successes:

Describe any program highlights or specific successes/accomplishments achieved this past year, if not already noted elsewhere. Also feel free to provide any vignettes or quotes that help illustrate positive experiences and successful outcomes.

H. Challenges/Barriers:

Provide information about some of the specific barriers families encounter in accessing services, and challenges you face in assisting families in getting the necessary services they require to support their family member at home.

I. Ideas/Needs for Future Development:

Describe any ideas/plans you have for addressing future needs and program initiatives.

Family Leadership Programs Annual Report -- (SAMPLE)

Program Name:		Region:	
Agency:		Person Completing Report:	
Fiscal Year: FY		Date of Report:	Click here to enter a date.

A. Information on Program Participants (these may be duplicate counts):

1) Number of individuals who participated in Family Leadership Series this FY?	
2) Number of individuals who participated in Other Trainings, Events, and Activities?	

List Other Family Leadership Trainings, Events and Activities

Family Leadership Trainings, Events & Activities	# of Participants	Comments/Highlights

3) Total number of individuals who participated in Family Leadership Series, plus Other Trainings, Events and Activities Offered by program	
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4) Provide the information on the following ages ranges of family members who participated in the Family Leadership Series Only :			
Under 5 Years of Age		6 Years of Age up to 14th Birthday	
14 Years of Age up to 22nd Birthday		Over 22 Years of Age	

5) Provide any other descriptive/demographic information about the family members who are participating in program activities in order to get a better understanding of the profiles of families you are seeing. For example, include information on the cultural/ethnic diversity of families, number of families for whom English is not their first language, single parents, etc.

Family Leadership Series

Please provide a brief description of Family Leadership Series, Including any program highlights, vignettes, quotes, etc.

Other Training Opportunities and Resources

How do you inform families of other training/education opportunities and/or other beneficial resources?

Community Partnerships/Collaboration

Provide a brief description of any partnerships or collaborative initiative with other organizations developed this past year, if it has not already been noted above.

Geographical Accessibility

What strategies have you used to ensure that families across your region, who live in more remote areas, have access to the Family Leadership Series and other program activities?

Family Involvement

What strategies have you used to encourage Family Leadership graduates to continue their involvement with the Family Leadership project and other leadership/advocacy opportunities?

Ideas/Needs for Future Development

Describe any ideas/plans you have for addressing future needs and program initiatives.