

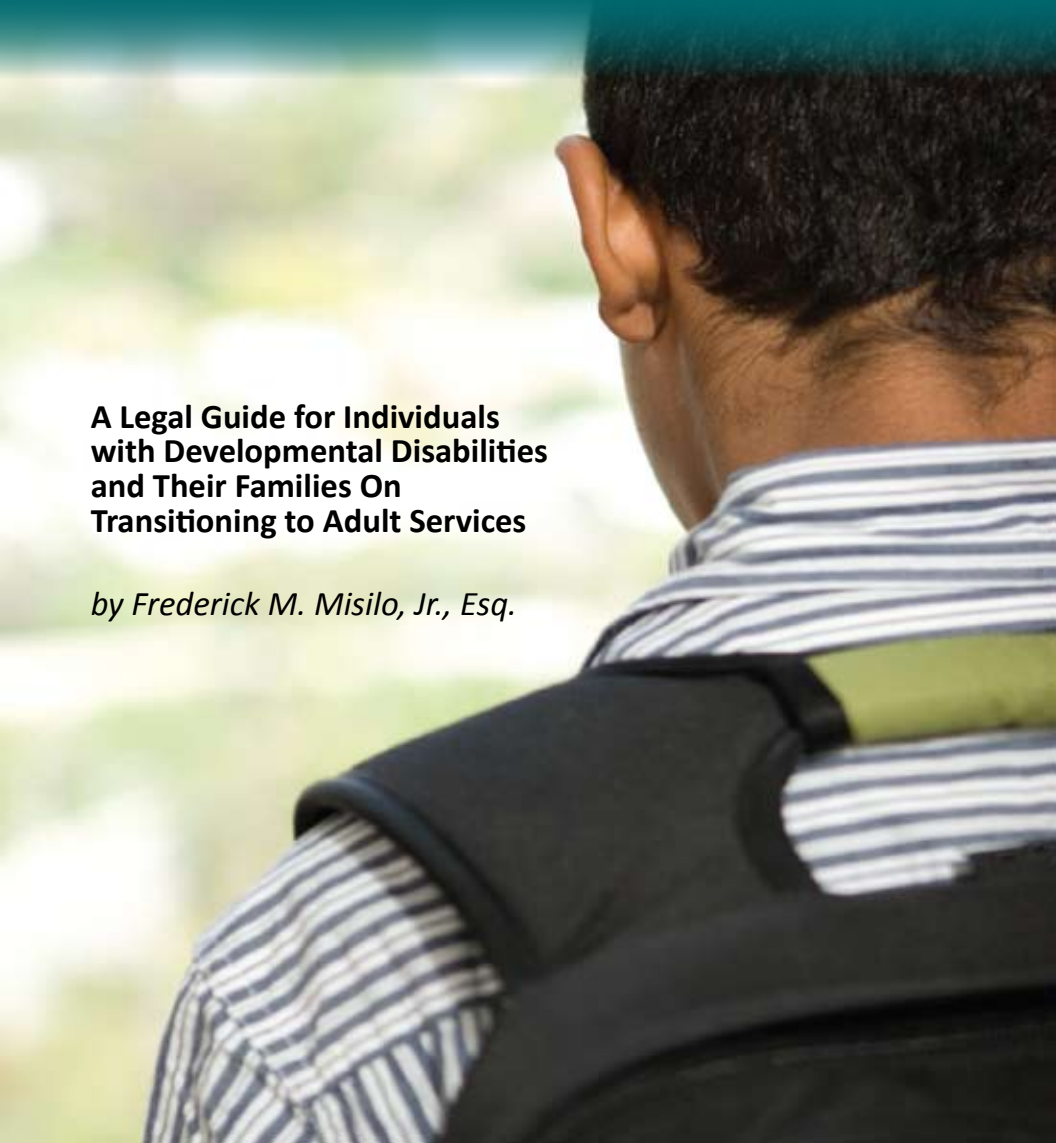


COMING OF AGE IN MASSACHUSETTS

A Legal Resource Guide

**A Legal Guide for Individuals
with Developmental Disabilities
and Their Families On
Transitioning to Adult Services**

by Frederick M. Misilo, Jr., Esq.



Welcome!

Planning is a key ingredient in any successful journey. The journey from special education to adult services inevitably occurs due to the mere passage of time. Making that journey as smoothly and successfully as possible requires a knowledge of what to expect and being prepared to make important planning decisions. The purpose of this legal guide is to provide you with information about the journey. Hopefully you will find it helpful whether you are years away from adult services or if the transition is imminent.

In the following pages, you will find information about the legal consequences of turning eighteen years old, important benefits from the state and federal governments, options to assist in personal, financial and health-care decision-making and the importance of special needs planning by parents and other family members.

Table Of Contents

PAGE	TOPIC
4	About the Author
5	Legal Emancipation—Turning Eighteen
6	Options for Personal, Financial & Healthcare Decision-Making
10	Transition to Federal Government Benefits
12	Note About Parent’s Health Insurance Coverage
14	Transition to Adult Human Service Support Systems
17	DDS 688 Transition Coordinator
18	DDS Eligibility Process
20	A Note About Eligibility for Services at DDS
21	Determination of Needed Supports for Eligible Individuals
23	Special Needs Planning By Parents
24	A Note About Life Insurance
25	Special Needs Trust Expenditures List
26	The Life-Planning Document
28	A Paradigm for Planning Diagram
29	ABLE Act of 2009
30	Glossary of Legal Terms
34	Contacts
	Appendix CD Inside Back Cover

2nd Edition Acknowledgements

Since the First Edition of *Coming of Age* was published in 2007, significant changes have taken place in Massachusetts which impact individuals with developmental disabilities upon reaching age eighteen – the legal age of emancipation in Massachusetts. In 2009, Massachusetts adopted the Uniform Probate Code which transformed guardianship and conservatorship law and procedure. These changes alone required a revision of the First Edition. Also, the name of the agency primarily responsible for administering services on behalf of children with developmental disabilities and for adults with an intellectual disability has been changed to the Department of Developmental Services.

Finally, we have witnessed an economic recession in the last two years unlike anything since the Great Depression. Such an economic downturn has had and will likely continue to have profound influence on the rationing of federal and state resources available to individuals with developmental disabilities. As a result, it will become increasingly important for families to engage in aggressive financial and special needs planning so that a sufficient amount of resources are available to supplement available government benefits and services.

I would like to acknowledge the contributions of Geoff Misilo, Esq. for his research on the Uniform Probate Code and for his assistance in revising the Options for Personal, Financial and Healthcare Decision-Making of this transition guide. Also, my thanks to Sara Murphy, Marketing Manager of Fletcher, Tilton & Whipple, P.C., for her editorial and creative design work. Finally, I remain grateful to my friend and colleague Theresa M. Varnet, Esq., Of-Counsel, Fletcher, Tilton & Whipple, P.C. for her inspiration and leadership in special needs planning and advocacy on behalf of individuals with disabilities and their families.

Frederick M. Misilo, Jr., Esq.
January, 2010

About The Author



With over twenty years of experience practicing law, Attorney Frederick M. Misilo, Jr., Esq. is a frequent lecturer on special needs planning, estate planning and elder law. He is the Special Needs & Elder Law Practice Group Leader at Fletcher, Tilton & Whipple, P.C. and has offices in Framingham, Hyannis and Worcester.

He serves as President of the Arc of Massachusetts, Inc. and is Chairperson of the Board of Directors of the Cooperative for Human Services, Inc., a well-respected human service agency with over thirty years of experience providing community-based residential and guardianship services to individuals with intellectual disabilities. He is a member of the Massachusetts Chapter and the National Chapter of the National Academy of Elder Law Attorneys and is a member of the Academy of Special Needs Planners. He is also the immediate past Chairperson of the Worcester Regional Chamber of Commerce.

Attorney Misilo was selected by the Chief Justice of the Massachusetts Probate and Family Court to train attorneys on their responsibilities reviewing the performance of Trustees of supplemental needs trusts as part of the Client Trust Fund Project. Also, in 2009, Attorney Misilo was selected by the Chief Justice of the Probate and Family Court to serve on a committee, along with Judges, other attorneys and court personnel, on preparing for the implementation of the Uniform Probate Code in Massachusetts.

Mr. Misilo is admitted to practice law in the Commonwealth of Massachusetts and the State of Rhode Island. He holds a law degree from Suffolk University Law School, a Master's Degree in Education (Administration, Planning and Social Policy concentration) from Harvard University, and an undergraduate degree from the University of Massachusetts at Amherst.

His past positions have included serving as Deputy Commissioner for the Massachusetts Department of Developmental Services and as Executive Director of Harbor Area Community Services, Inc. in Boston, Massachusetts. He has served on numerous elected and appointed boards and commissions, including the Holden, MA Board of Selectmen from 1989 to 1998.

Legal Emancipation & Turning Eighteen

When a person turns eighteen years of age, in the eyes of the law, that person is presumed to have the capacity to make informed legal, financial and health care decisions. In other words, when a person reaches the age of eighteen years, parents are no longer able to make decisions on their son or daughter's behalf. This also means that, in most circumstances, parents are not entitled to receive personal information about their son or daughter from health care providers, human service professionals, educational services and others.

Of course, not everyone is able to make the best decisions immediately upon turning eighteen years old. In fact, most people can use some help in making informed decisions throughout their lifetime. In some cases, some individuals may need protection from making really bad decisions that could result in financial loss, serious injury or worse. In the next section, you will read about options that need to be considered when a person with a developmental disability needs some help in personal, financial and/or health care decision-making.



Options for Personal, Financial & Health Care Decision-Making

(From Least To Most Restrictive)

1. Representative Payee

For persons receiving government benefit checks, consider obtaining a representative payee to manage these funds. Benefit checks are sent to the representative payee who manages them and spends them for the benefit of the individual with a disability. The representative payee has authority only over income from the particular checks for which he/she is payee. Representative payees for recipients of Supplemental Security Income are required to file annual reports to the Social Security Administration. Additional information on the Representative Payee Program of the Social Security Administration can be obtained at www.socialsecurity.gov/payee.

2. Appointment of an Advocate

A person may appoint another person to act as their advocate in educational, adult services or health related matters. This advocate can obtain documents, attend meetings and generally speak up for an individual in important ways. An advocate normally is limited to specific areas, such as special education advocacy, transition service planning, etc.

3. Durable Power of Attorney for Property

A durable power of attorney (“DPOA”) for property is useful where a person has a mild or moderate incapacity and is capable of choosing a trusted person to handle his/her property. The DPOA is a legal document in which a person, termed “the Principal” gives a person, “the Attorney-in-Fact,” the legal

continued on next page

Options Recap

authority to handle his or her financial affairs. A DPOA is normally revocable. This means that the DPOA can be revoked or changed at anytime by the Principal so long as the Principal has the mental capacity to take such action. Also, the Principal who creates the DPOA retains decision-making authority of his or her property. A benefit of a DPOA is that it is a flexible arrangement which does not require a finding of incapacity of the Principal even though he or she may need some assistance in decision-making. At the same time, a drawback can be that a Principal with a quick temper or who acts impulsively without thinking things through may remove their Attorney-in-Fact at a time when assistance is needed the most.

4. Health Care Proxy

A health care proxy is a legal document that enables a competent individual, (the “Principal”), to designate a health care agent to make health care decisions should the principal become unable to make or communicate health care decisions. The health care agent is permitted to make all health care decisions, including decisions about life sustaining treatment. The proxy must be a written document that is signed by the Principal and witnessed by two adults. The Principal may revoke the proxy at any time and in any manner that demonstrates specific intent to terminate it. A health care proxy goes into effect when the Principal’s doctor determines in writing that the Principal can no longer make or communicate health care decisions.

LEAST

**Representative
Payee**

**Appointment of
an Advocate**

**Durable Power
of Attorney for
Property**

Health Care Proxy

**Special Bank
Accounts
or Custodial
Accounts**

Trusts

Conservatorship

Guardianship

MOST

5. Special Bank or Custodial Accounts

Joint bank accounts can be created to prevent rash expenditures. Arrangements can be made for a person's benefit check, such as SSDI or SSI, to be sent directly to the bank as a direct deposit. Additionally, a permanent withdrawal order can be arranged with the bank, authorizing the bank to send certain sums of money on a regular basis to a specified party, such as a landlord or the person who is disabled for pocket money, thus providing structure to allow for budgeting and money management. Some financial planners and attorneys will assist a client with payment of regular monthly expenses through the use of a custodial account that operates similarly as a permanent withdrawal order. Through the use of a custodial account, payment can be made for goods and services on a regular and/or on an as-needed basis.

6. Trusts

Trusts may be an appropriate alternative to conservatorship. A trust is a legal plan for placing funds and other assets in the control of a trustee for the benefit of an individual. Trusts for the benefit of a person who has a disability should be established with the help of a lawyer experienced in trusts and familiar with the law relating to government disability benefits. A trust set up without regard to the eligibility laws may disqualify a person who is disabled for MASS Health, SSI and other important government benefits.

7. Conservatorship

Conservatorship should be considered for persons who are unable to make informed financial decisions and who have income from sources other than government benefit checks. A conservator handles only financial affairs, allowing the person to make personal decisions. The court may appoint a conservator if the person is unable to properly care for his or her property. Physical incapacity is also a legally sufficient reason for appointing a conservator, provided the person agrees to the appointment. The Probate Court places many requirements on conservators. Conservators must act in the best fiduciary interests of the individual, involve the protected person in decision making, and work to develop or restore the individual's ability to manage his own affairs. The Court also monitors the performance of conservators by reviewing annual accounts and plans created by the conservators.

8. Guardianship

Guardianship is an option for persons who are incapable of making decisions about their personal affairs. Massachusetts has adopted the Uniform Probate Code (“the Code”) which requires evidence of incapacity and disability rather than incompetence. This incapacity or disability evidence helps to focus on functional limitations. A Clinical Team Report (“CTR”) must be filed with a guardianship petition on behalf of a person with an intellectual disability. The CTR is a detailed report on the functional ability of the person who is subject to the guardianship proceeding which must be signed by a physician, licensed social worker and licensed psychologist. The CTR assists the Court in evaluating the need for guardianship. A Medical Certificate must be filed on behalf of a person with a mental health or physical disability. A sample CTR and Medical Certificate is contained in the CD found at the back of this guide.

The Code favors limited guardianship rather than a full or all-encompassing guardianship. The Code also creates a requirement that guardians file an annual written report covering important areas of life such as, living arrangements (including planned changes) and services. A copy of the Guardian Report is contained in the CD found at the back of this book. Also, the Code requires annual visits by the guardian.

As you can see, there are a number of options for personal, financial and healthcare decision-making. The best practice is to explore least restrictive options prior to moving toward more restrictive options. By doing so, an individualized plan of support can be provided without unduly restricting a person’s right to make decisions he or she may be competent to make on his or her own.

Transition to Federal Government Benefits

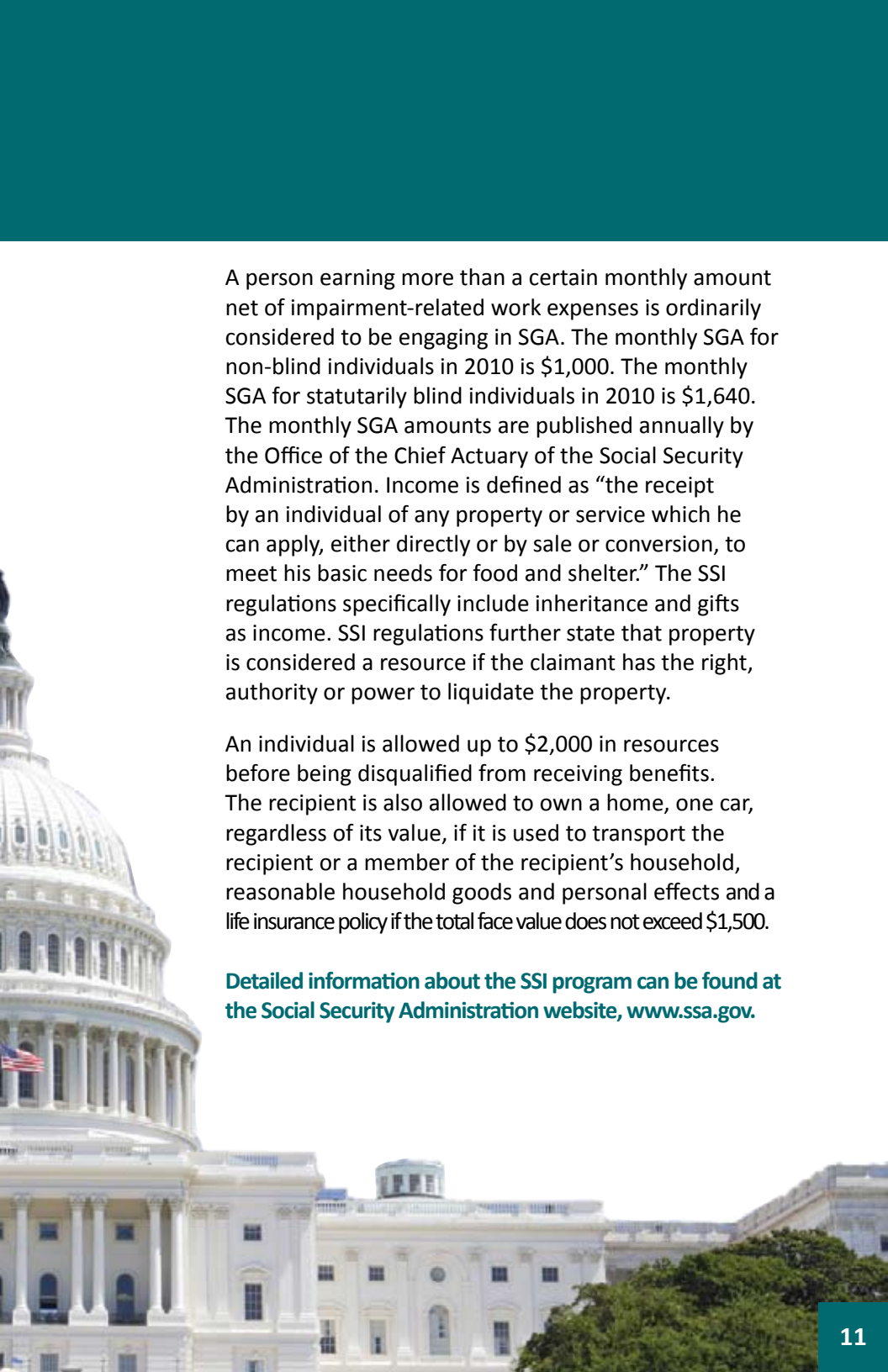
Government Benefits Based on Financial Need

Supplemental Security Income (SSI)

Two important programs for persons with disabilities are Supplemental Security Income (SSI) and Medicaid. In Massachusetts, Medicaid is referred to as Mass Health. Upon attaining the age of eighteen years, a person is eligible for SSI and Medicaid even if he or she is living with their parents and without the parent's assets and income being deemed to him or her. It is important for parents to realize that eligibility for SSI and Medicaid may be critical to an individual who has a disability. SSI provides a monthly cash payment. The amount of the cash payment is based on the income level and living arrangement of the individual. The SSI payment will increase every year to keep up with the cost of living.

Eligibility for SSI

To be eligible for SSI you must be age 65 or older, blind or have a disability and have limited income and resources according to the guidelines of the program. A person is considered to have a disability if that person has a medically determined disability expected to last at least 12 months or result in death and be unable to engage in "substantial gainful activity" (SGA).



A person earning more than a certain monthly amount net of impairment-related work expenses is ordinarily considered to be engaging in SGA. The monthly SGA for non-blind individuals in 2010 is \$1,000. The monthly SGA for statutorily blind individuals in 2010 is \$1,640. The monthly SGA amounts are published annually by the Office of the Chief Actuary of the Social Security Administration. Income is defined as “the receipt by an individual of any property or service which he can apply, either directly or by sale or conversion, to meet his basic needs for food and shelter.” The SSI regulations specifically include inheritance and gifts as income. SSI regulations further state that property is considered a resource if the claimant has the right, authority or power to liquidate the property.

An individual is allowed up to \$2,000 in resources before being disqualified from receiving benefits. The recipient is also allowed to own a home, one car, regardless of its value, if it is used to transport the recipient or a member of the recipient’s household, reasonable household goods and personal effects and a life insurance policy if the total face value does not exceed \$1,500.

Detailed information about the SSI program can be found at the Social Security Administration website, www.ssa.gov.



A Note About Parent's Health Insurance Coverage

Some parents may feel that they do not have to be concerned with federal medical assistance because their adult child is covered with a private health insurance policy. Often the coverage in programs that insure persons who are disabled is minimal and the cost for private medical coverage may be prohibitive in the future. In some cases, while the child presently has medical insurance, his or her medical coverage may terminate upon the death or retirement of the parent.

Many parents are not aware that they can continue their group plan health care coverage for their dependent adult child after their child graduates or leaves school. You will need to check with your personnel department to see if your company health insurance plan has this option available.

Most companies require that you notify them within 3 months of your child's 19th birthday that he or she is disabled and is dependent on you for care. If you do not notify your health insurance carrier of your child's special needs, they may drop your child from your coverage.

Federal Benefits NOT Based on Financial Need

An adult who is unmarried, age 18 or older and who has had a disability that started before age 22 may be eligible for Social Security disability benefits if a parent who has worked long enough under Social Security has died or is receiving Social Security retirement or disability benefits. This benefit is sometimes referred to as Disabled Adult Child (DAC) benefits. To be eligible, the adult with a disability may be a biological child, an adopted child, and in some cases, a stepchild, grandchild or step grandchild of the worker.

A person will be considered disabled if that person is unable to engage in SGA (see Eligibility for SSI on page 10).

Additionally, a person who has been receiving Social Security disability benefits for at least two years will start receiving Medicare, a federal health insurance program.

Transition to Adult Human Service Support Systems

We wish to gratefully acknowledge that this section is derived primarily from “The Road Forward” (2nd Edition, May 2007) published by The DDS Central Middlesex Area Office.

WHAT is Chapter 688?

Chapter 688 is a law enacted in 1983 to provide a two-year planning process for young adults with severe disabilities who will lose their entitlement to special education at the age of 22, or at the time of graduation from high school, whichever comes first. The law creates a single point of entry into the adult human service system.

WHO is Eligible for Chapter 688?

To be eligible for Chapter 688 services, a person must:

- Be receiving special education paid for by the Commonwealth of Massachusetts,
- Need continuing habilitative services at the time of turning 22 or graduating from special education, and
- Be unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school.

An individual is automatically eligible for Chapter 688 if receiving SSI, SSDI, or registered with the Massachusetts Commission for the Blind.

HOW is a 688 Referral Made?

Only the local school system, also known as the Local Education Authority or LEA, can make a 688 referral. The referral must be made while the student is still in school. The local school system typically decides which human service agency might best meet the student's needs as an adult and sends the referral directly to that agency. If an individual is being referred to DDS, the referral typically is sent directly to one of the DDS area offices. If a student or parent believes that a 688 referral has not been made, but should have been, they should contact the Special Education Department at the school, or the Director of Special Education Services for the school system.

WHEN Should a 688 Referral Be Made?

Chapter 688 requires the school system to make the 688 referral two years before a student graduates or turns 22, whichever is earlier. In order to facilitate the planning process, DDS prefers to have the 688 referral even earlier than required by Chapter 688. DDS suggests that referrals be made at age 18 to coincide with DDS adult eligibility age requirements. Referrals that are made less than 2 years before graduation do not afford adequate planning time to assist a student in the most meaningful way possible. Students or families who are concerned about the timing of a 688 referral should contact both the school system and the local DDS area office, if they feel DDS would likely become the Transitional Agency.

If A Student is Already Known to DDS, Is a 688 Referral Still Necessary?

YES. Even though some individuals with an intellectual disability receive DDS services as children, a referral should still be made. The 688 referral starts the DDS planning process for the individual student.

What is the “SPED DATE” And Why Is It Important?

The special education date (or “sped date”) is the date on which a student is planning to leave special education and school. Typically, the sped date is either the student’s expected date of graduation or 22nd birthday. The sped date is used in the 688 referral process as the reference date for planning. Students leaving on short notice in advance of the sped date specified on the 688 referral may not have the benefit of adequate planning time to assist with a smooth, well-planned transition.

What happens if a Student Leaves School Without a 688 Referral?

If a student leaves school without a 688 referral being made, the student is not eligible for planning through 688. The student can still apply to DDS or other state agencies serving adults at any time, as any citizen could.

What is the Transitional Agency (TA)?

The Transitional Agency (TA), sometimes referred to as the Lead Agency, is the state agency that receives the 688 referral. It is the agency that the local school system feels will best meet the student’s future needs as an adult. The TA is responsible to assist the individual in planning to move from special education services into adult life. DDS is one such agency. Other Transitional Agencies include the Department of Mental Health and the Massachusetts Rehabilitation Commission.

DDS 688 Transition Coordinator

What is a DDS Transition Coordinator?

A DDS Transition Coordinator, sometimes called the “688 Coordinator,” is a case manager who works at the local DDS Area Office. The Transition Coordinator’s case load consists of individuals age 18-22 who have been found eligible for adult supports through DDS. The Transition Coordinator is the individual’s primary link to information and assistance from DDS during the transition from special education to adult life. The Transition Coordinator will help the individual and family understand what DDS can offer and assist with identifying and securing requested supports, subject to prioritization for those supports. Following graduation and transition into adult supports, an individual’s case will be transferred to an adult Service Coordinator within the Area Office.



DDS Eligibility Process

Who is Eligible for Adult Supports From DDS?

A person, 18 or older meets the criteria for eligibility for services and supports provided, purchased or arranged by the Department if the individual:

1. is domiciled in the Commonwealth of Massachusetts
2. is a person with mental retardation as defined in 115 CMR 2.01 (this information can be found under the “regulations and policies” link at www.mass.gov/DDS)

What is the Application Process?

Application Process:

The application process is initiated by sending an application form (Application for DDS Eligibility) to the DDS Eligibility Team. This form contains basic information about the applicant that enables the Regional Eligibility Specialist to make contact with the applicant to arrange an interview. The Regional Eligibility Team may receive telephone requests for eligibility determination and may complete the application form via telephone.

Intake Process:

When the application is received, an eligibility specialist from the Regional Eligibility Team will contact the applicant, guardian, or referral source within 10 days of receipt of a completed application form to arrange for an intake interview. This interview can take place at the DDS Regional Office, the Area Office, or other location. The intake process generally consists of the initial interview, the gathering of relevant information which may include requests for additional assessments or testing and a clinical assessment that assists the DDS to identify needed resources.

Eligibility Determination:

The applicant or guardian is responsible for obtaining all relevant information needed to determine eligibility and must make every reasonable effort to ensure that the information is received by the DDS in a timely manner. When all information is gathered and assessments completed, the Regional Eligibility Team Psychologist conducts a review and makes the determination decision after conferring with members of the Eligibility Team. The Regional Eligibility Team is asked to make a determination within 60 days. If no final determination can be reached after 60 days due to incomplete information, the DDS may extend the process for an additional 60 days. After 120 days, the Regional Eligibility Manager will send a formal decision letter based on the information that has been made available to DDS. This decision is communicated to the applicant or his/her guardian and to the appropriate DDS Area Office.

Appeals

Individuals have the right to appeal any findings contained in the eligibility letter within 30 days of receiving the letter and also have the right to a Fair Hearing before an impartial hearing officer.

A Note about Eligibility for Services at the Department of Developmental Services

As individuals with an intellectual or other developmental disability approach age eighteen, their parents may assume that their son or daughter will be found eligible for services as an adult by the Department of Developmental Services (DDS). This is particularly true for individuals who have, in the past, received early intervention services, special education and, perhaps, family support from the DDS. Many applicants may have also participated in Special Olympics and/or Best Buddies at various times in their childhood. In order to be eligible for services from the DDS before turning eighteen years old, one must be found to have a developmental disability. This definition may include those who have been found to have, for example, a pervasive developmental delay, a disorder on the autism spectrum, or a significant learning disability. However, participation in early intervention, special education, family support funded by the DDS or other services for individuals with developmental disabilities does not bear much relevance in eligibility determinations for adult services. What is necessary for eligibility for adult services at the DDS is the existence of reports, tests and evaluations, preferably conducted prior to age eighteen, which document significant deficits in intellectual functioning, deficits in two or more areas in adaptive behavior and that such deficits became evident during the developmental period.

Many parents and individuals are shocked to learn that an obvious need for services and supports due to a significant intellectual or developmental disability may still not qualify them for adult services. In fact, many individuals who have significant strengths co-existing with significant weaknesses in certain areas of functioning, may find that the very existence of those strengths exclude them from eligibility for adult services. For example, a person who scores average in verbal ability but who has significant deficits in performance ability in psychological testing may be found ineligible when these two abilities are combined to produce a full scale performance score. Also, individuals who have an autism spectrum disorder may be found ineligible due to average scores in isolated areas of performance even when these average scores do not translate into tangible life skills.

Applicants who have been rejected for adult services at the Department of Developmental Services have a right to an administrative hearing before an impartial hearing officer. In order for a hearing officer to reverse an ineligibility determination, he/she must have enough evidence to determine that the state agency was incorrect. To do this, it is very important that evidence, preferably through an expert witness such as a licensed psychologist, demonstrates that the eligibility determination was wrong. Since the DDS is represented at these administrative hearings by its own attorneys, it is strongly recommended that appellants retain counsel to represent them at the hearing. If an ineligibility determination is not appealed within the appropriate appeal period, a future application for adult services will be denied unless new evidence can be brought forward to establish eligibility.

Determination of Needed Supports for Eligible Individuals

MASSCAP

To determine whether a requested support or service will be given to an individual, DDS uses a system called MASSCAP. MASSCAP is a clinical assessment tool that determines the need for a particular service. The MASSCAP consists of three assessment tools. One tool is called *The Inventory for Client and Agency Planning* (ICAP). ICAP is an automated tool that assesses an individual's adaptive functioning. Its scoring is empirical and gives a functional perspective on the individual. The areas assessed by the ICAP are: motor skills, social and communication skills, personal living skills, and community living skills. An individual tested using ICAP is given a score ranging for zero to three points. Zero points means that individual "never, or rarely does well" in that area, while three means "does very well" in that area. This information is then entered into the ICAP application to determine the total ICAP score.

The second tool of the MASSCAP is the *Consumer and Care Giver Assessment* (CCA). The CCA allows DDS to analyze the resources and supports that are currently in place for the individual, provides a source of information about what could be put in place to further assist the individual, and provide information to assist in evaluating the caregiver's capacities. It is a combination of descriptive and numerical information. The CCA looks at the current caregiver and their ability to continue to provide support in a manner that keeps the individual safe from harm.

Determination of Needed Supports for Eligible Individuals

Continued

The third tool used by MASSCAP is the application of clinical judgment through the use of other assessments and consideration of other relevant factors concerning the individual. An assessor may seek additional information to determine the individual's need for services. These supplemental assessments can range from psychological tests to additional function behavioral tests that may better define an individual's need. The decision to include additional assessments is strictly at the department's discretion.

Once the MASSCAP has been completed and the individual is found to have a need for service, the next step in the process is to determine the prioritization level for that service within existing resources. Prioritization is an administrative tool that separates priority into two groups, Priority 1 and Priority 2. Priority 1 means that provision, purchase, or arrangement of supports available through the Department is necessary to protect the health or safety of the individual or others. Priority 2 means that provision, purchase, or arrangement of supports available through the Department is necessary to meet one or more of the individual's needs or to achieve one or more of the needs identified in his or her Individual Service Plan. Under Priority 1 needs, the service planning should be initiated and services should be arranged or provided within 90 days. Under Priority 2 needs, the Department should be engaged in active planning with the family or individual within 90 days and services should be provided or arranged within 12-18 months.

Special Needs Planning By Parents

It is an obvious fact that parents want to do as much as possible to plan for a safe, secure and enjoyable life for their son or daughter with a developmental disability. Through an effective special needs plan, one can enjoy a meaningful lifestyle that encourages independent, self-sufficiency and enjoyment.

As noted throughout this handbook, it is likely that at some point in his or her life, a person with a disability will need government benefits such as SSI, Medicaid, residential support, job training and other support services. Parents need to plan so that their son or daughter can maximize opportunities to receive government benefits and services. Parents must recognize that without careful planning, an inheritance may make their child ineligible for benefits which can be far more valuable, long-term, than the inheritance. In some cases, the more a person inherits, the worse off he or she may be with regard to eligibility for certain benefits. Government benefits are important because it is seldom possible for the average family to leave sufficient funds to provide sufficient services and supports over the lifetime of their son or daughter with a disability. The cost of services and supports varies tremendously depending on the area in which the individual lives and the nature and degree of the individual's disability. It is difficult to predict what these costs will be twenty or thirty years from now. Given the 2008 market crash and the ensuing economic recession, state and federal government resources for disability services are not likely to grow in the near future.

Parents have an opportunity to supplement government benefits with family assets through careful special needs planning. There are a variety of approaches to consider, including the creation and funding of a special needs trust, which holds assets for the benefit of a person which does not affect that person's entitlement to needs-based government benefits such as SSI or Medicaid. Upon the death of the beneficiary, the assets held in a special needs trust which funded by the beneficiary's family are distributed to those persons identified in the trust and not the government.



A Note About Life Insurance

Since most special needs trusts created by parents for their son or daughter are funded upon the death of one or both parents, it is an obvious and universally accepted fact that life insurance is a common way to fund, in part, special needs trusts. Parents must have basic understanding of life insurance in order to make informed decisions when purchasing these products. A naïve misunderstanding or lack of knowledge may result in unintended negative consequences such as unnecessary estate taxes, inadequate funding, higher than necessary premiums and loss of death benefits.

An article entitled "Special Needs Planning and Life Insurance," written by Attorney Frederick M. Misilo, Jr., Esq. is contained in the CD which accompanies this booklet.

Special Needs Trust Expenditures Can Include But Are Not Limited To:

- Additional physician visits (over the Medicaid limit)
- Appliances
- Bicycle, fitness equipment, personal trainer
- Bottled water
- Bus or train pass
- Cab scrip
- Cable TV bill
- Car/Van: fuel, repairs, maintenance, insurance
- Cell phone
- Club dues
- Clothing
- Computer, internet service, software, training, repairs
- Curtains, blinds, drapes
- Dental work, eyeglasses, hearing aids, batteries not covered
- Dermatology not covered by Medicaid
- Drugs unavailable through Medicaid (non-generic)
- Entertainment, movie or theater tickets
- Furniture
- Haircuts, manicures, pedicures, and other salon services
- Health club membership
- Hobby supplies
- House cleaning/maid service
- Incontinence supplies and equipment
- Laundromat/Dry Cleaners
- Legal fees/Guardian fees
- Lessons, classes or college tuition and fees
- Linen
- Massage, Acupuncture/Acupressure, Roling and other alternative treatments
- Musical instruments
- Non-food grocery items, such as: laundry soap, bleach, etc. tissues, household cleaning products, paper towels, napkins, deodorant, soap, personal hygiene products
- Orthopedic shoes/podiatry
- Over the counter medications
- Oversight, monitoring, and advocacy
- Painting and music therapy
- Payment of private health insurance premiums
- Personal attendant services beyond Medicaid limits
- Pets, pet supplies/food, pet care (veterinarian bills, etc.)
- Private counseling
- Record/Book clubs
- Rehabilitation and physical therapy beyond Medicaid limits
- Respite care
- Telephone bill or phone card
- TV, VCR, DVD player, stereo
- Vacations
- Vitamins, Herbs
- Wheelchairs not covered by Medicaid; repairs, driving gloves

CAUTION: Do not distribute funds directly to the beneficiary. The above goods and services must be paid directly from the trust to the vendor or service provider.

The Life-Planning Document

A life-planning document, sometimes called a “letter of intent” or “letter of instructions,” can serve as a core element of a special needs plan. It also provides critical information to future service providers and trustees.

Such a document can contain the following information about:

- Personality characteristics and personal preferences.
- Family members.
- Medical history, list of physicians and other individuals and organizations providing support and services.
- Friends, pets, favorite foods, likes and dislikes, and hopes and expectations.

You should develop a life-planning document when it is likely that your son or daughter is going to live outside your home sometime in the future and will require a good deal of support and services to maintain and enhance his or her quality of life. A form of a life planning document is contained in the included CD.

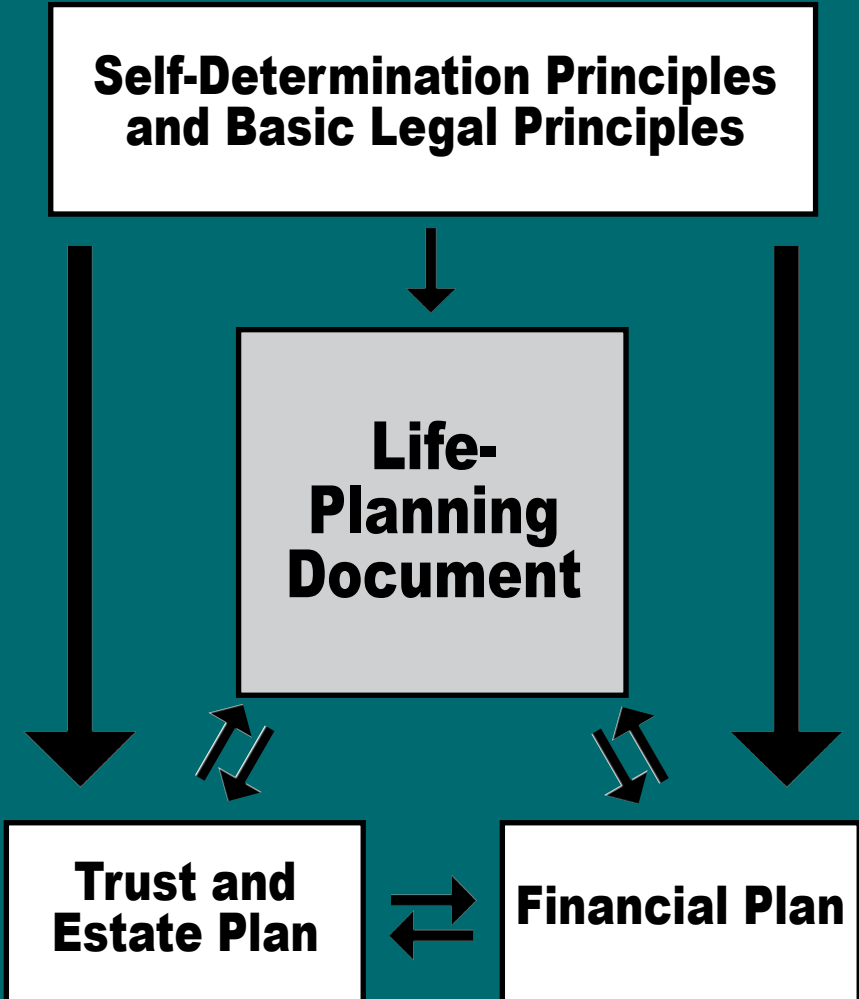


A life-planning document is important because many people may be unable to accurately convey pertinent facts and information about themselves to others. The life-planning document gives parents an opportunity to communicate their perspective on and knowledge of their son or daughter regarding a wide range of topics. Combined with your disabled family member's self-determination, the life-planning document contains the core considerations that providers should heed when providing support and services.

The amount of time and energy required to prepare a life-planning document varies widely, depending on how much information you want to include and whether you plan to write it by hand or on a computer. Generally speaking, count on it taking six to eight hours.

The initial effort can be considerable and daunting as parents try to think of everything to include. Rest assured that updates are usually much easier. It is recommended that the life-planning document be updated at least once a year – for instance using a birthday may help to remember that it is time to update the document. Time has a way of flying and without a trigger date to help remember, the need for an update may be overlooked. If parents find it difficult to write a life-planning document, I recommend that you work with a qualified person who can facilitate a discussion and help to write the document. This person can be a certified life planner, certified care manager, or someone with a social service, educational or journalistic background. In short, parents should rely on someone who can listen well to the story and who can write it in coherent, understandable terms.

A Paradigm for Planning



ABLE Act of 2009

At the time of this printing, the ABLE Act of 2009 is **pending** before Congress with the likelihood that it will be passed.

The Act has two main purposes:

(1) To encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life,

and

(2) To provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, the Medicaid program under title XIX of the Social Security Act, the supplemental security income program under title XVI of such Act, the beneficiary's employment, and other sources.

These protected funds will be placed in a savings account like a 529 college savings account. These accounts would be tax-exempt so long as certain rules are met. The money can grow tax free like an IRA. These funds may be used for education, transportation, employment support, health, prevention, wellness, life necessities, and other approved expenses. Unlike 529 college savings plans, ABLE accounts will be federally regulated so they will be uniform throughout the country. These accounts could also be managed by pooled trusts, if the individual or family so chooses. A significant drawback to ABLE accounts will be that the funds remaining in the accounts at the individual's death would be used to "pay back" the state Medicaid program up to the value of services provided to the individual during life.

**** Please note: as stated at the top of this page, the ABLE Act of 2009 has NOT been passed as of the printing date of this booklet. ****

Glossary of Legal Terms

A

Advocacy: The active support of a legal cause (example: obtaining government benefits through representation before courts and governmental agencies).

Attorney-in-fact: The person named to act for another person under a power of attorney.

B

Beneficiary (under a trust): The person who receives the equitable title to trust property and hence the right to benefit from that property according to the grantor's instructions.

Beneficiary (under a will): A generic term for a person who receives property under a will.

C

Charitable Lead Trust: A trust in which a charity obtains benefits for a specified period of time, after which the benefits return to the grantor or the grantor's family.

Charitable Remainder Trust: A trust in which the grantor or the grantor's family retains benefits until a specified time, after which the remainder passes to a charity.

Charitable Trust: A trust created for a charitable beneficiary.

D

Discretionary Trust: A trust giving the trustee discretion with respect to payments to and on behalf of the trust beneficiary.

Donee: The recipient of a gift.

Donor: The maker of a gift.

E

Estate Tax: A tax on a decedent's transfer of property at death.

Executor: The person named under the will to act as the decedent's personal representative with respect to the administration and distribution of the decedent's estate.

F

Fiduciary: A person having the legal duty to act for the benefit of another, such as an attorney, an executor or a trustee. A fiduciary is subject to obligations and responsibilities prescribed by law and is personally liable for any wrongdoing.

G

Generation-Skipping Transfer Tax: An additional tax on certain transfers to beneficiaries who are more than one generation younger than the person transferring the property (example: a transfer from grandparent to grandchild).

Gift Tax: A tax on lifetime transfers of property for less than full and adequate consideration.

Gift Tax Annual Exclusion: The amount that a person may transfer to another annually without the imposition of a gift tax. Currently the gift tax annual exclusion amount is \$13,000.00 per donee.

Grantor: A person who creates a trust. Also called settler, trustor and donor.

Guardian: A person appointed by the court to be responsible for making decisions on behalf of a person deemed by a court to be incapable of making decisions and properly caring for himself/herself.

Guardian Ad Litem: A guardian appointed by the court to represent the interest of certain individuals incapable of representing themselves (such as minors, incompetents or unborn beneficiaries) in legal proceedings.

H

Health Care Proxy: A document appointing another person to make healthcare decisions in the event of incapacity or an inability to communicate.

Heir: A person entitled to take property of a decedent under state default rules for those persons dying without a valid will.

I

Intestate: Dying without a will.

JK

L

Life Insurance Trust: A trust which holds a life insurance policy and is designed to minimize transfer taxes and to provide additional funds to the estate. Policy premiums are covered through contributions to the trust which are structured to qualify for the annual gift tax exclusion.

MNO

P

“Pay Back” Requirement: Phrase used to refer to the requirement that any assets remaining in an OBRA '93(d)(4)(A) trust be used to reimburse the state (see below).

Power of Attorney: A document authorizing one person to act for another with respect to property.

Prudent Person Rule: A flexible legal investment standard that allows a fiduciary to purchase securities that a prudent person of discretion and intelligence would choose in order to earn a reasonable income and to preserve the principal.

QRS

T

Testamentary Trust: A trust created at the Grantor's death, pursuant to his or her will. Such trusts are subject to the jurisdiction of the Probate Court.

Trust Agreement: A document whereby property is conveyed by the owner of the property (the grantor) to the trust to be managed by the trustee for the benefit of others (the beneficiaries).

Trustee: The person who holds legal title to the trust property and who has the fiduciary duty to manage that property for the benefit of the trust beneficiary, according to the grantor's instructions and applicable trust law.

Supplemental Needs Trust (also known as Special Needs Trust): A trust where the trustee has the

discretion to make distributions on behalf of the beneficiary. The only limitation on the trustee's discretion is a directive that distributions be supplemental to otherwise available government benefits. The trust is designed to provide resources while still maintaining the beneficiary's eligibility for state and federal assistance programs.

There are two main types of supplemental needs trusts:

- **Third Person Supplemental Needs Trust:** A trust created for the benefit of a disabled person using funds contributed by another person, such as a parent. The assets contributed are held in trust for the benefit of the disabled person during his or her lifetime. Upon the disabled person's death, any remaining assets are not subject to a governmental payback provision.

- **OBRA '93 Trust:** Technical term for a trust funded with assets belonging to the disabled person for which the trust is created. Such trusts must meet the requirements prescribed by federal statute in order to maintain person's eligibility for governmental assistance.

An OBRA '93- Trust can be one of two types:

a) (d)(4)(A) Trust:

Technical term for an OBRA '93 Trust whereby a disabled person's assets are held in trust for the disabled person's benefit during his or her lifetime. Upon the disabled person's death, any assets remaining in the (d)(4)(A) Trust must be used to reimburse the state for governmental assistance received by the disabled person during his or her lifetime.

b) (d)(4)(C) Trust (also known as a Pooled Trust):

Technical term for an OBRA '93 Trust whereby the individual assets of several are pooled together into a common trust, usually managed by a charitable organization acting as trustee. Such pooling of assets leads to greater investment flexibility and rates of return while minimizing trust expenses. The collective assets are held in trust for the disabled persons' benefit during their lifetimes. Upon death, the remaining assets continue to be held in trust for the benefit of surviving and future contributors to the pooled fund.

U

Unified credit: A credit available to each individual to offset gift and state tax liability.

V

W

Will: A written document or oral declaration directing the disposition of the decedent's property upon the decedent's death.

XYZ



Contacts

Autism Society of America

47 Walnut Street
Wellesley Hills, MA 02481
www.autism-society.org
781-329-4244

Boston Center for Independent Living

60 Temple Place, 5th Floor
Boston, MA 02111-1324
www.bostoncil.org
617-318-6665

Bureau of Transitional Planning (BTP)

617-727-7600

Department of Education (DOE)

350 Main Street
Malden, MA 02148
www.doe.mass.edu

Department of Developmental Services (DDS)

www.mass.gov/DDS
617-727-5608

Department of Public Health (DPH)

250 Washington Street
Boston, MA 02108
www.mass.gov/dph
617-624-6000

Department of Social Services (DSS)

24 Farnsworth Street
Boston, MA 02210
www.mass.gov/dss
617-748-2000

Department of Transitional Assistance (DTA)

600 Washington Street
Boston, MA 02111
www.mass.gov/dta
800-249-2007

Disabled Persons Protection Commission (DPPC)

300 Granite Street, Suite 404
Braintree, MA 02184
www.mass.gov/dppc
800-426-9009

Division of Medical Assistance

www.mass.gov/masshealth
800-841-2900

The Arc of Massachusetts, Inc.

217 South Street
Waltham, MA 02453
781-891-6270
www.arcmass.org

Massachusetts Brain Injury Association (MBIA)

Westborough - E. Wareham - Pittsfield
www.biama.org
(800) 242-0030

Massachusetts Commission for the Blind (MCB)

48 Boylston Street
Boston, MA 02116
www.mass.gov/mcb
800-392-6450

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

150 Mt. Vernon St., Suite 550
Dorchester, MA 02125
www.mass.gov/mcdhh
617-740-1600

Massachusetts Developmental Disabilities Council (MDDC)

1150 Hancock Street
Quincy, MA 02169
www.mass.gov/mddc
617-770-7676

Mass. Families Organizing for Change

P.O. Box 61

Raynham, MA 02768

www.mfofc.org

800-406-3632

**Massachusetts Office on Disability
(MOD)**

1 Ashburton Place #1305

Boston, MA 02108

www.mass.gov/mod

617-727-7440

**Massachusetts Rehabilitation
Commission (MRC)**

27 Wormwood Street

Boston, MA 02110

www.mass.gov/mrc

617-204-3602

MedicareGenInfo Medicare

www.medicare.gov

800-MEDICARE

United Cerebral Palsy Association

1660 L Street, NW, Suite 700

Washington, DC 20036

www.ucp.org

617-926-5480



How Can We Help?

The attorneys at Fletcher, Tilton, & Whipple P.C. are experienced in representing clients with special needs issues. Our team, which includes attorneys, paralegals, trust and tax professionals and legal assistants, has extensive experience with special needs estate planning, guardianships and other less restrictive measures, DDS eligibility appeals, ISP appeals, supplemental needs trust management, as well as general advocacy for our clients. If you have a legal problem, we can assist you in getting it resolved.

For more information contact:

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Special Needs & Elder Law Practice Group

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FLETCHER, TILTON & WHIPPLE, P.C.
C O U N S E L O R S A T L A W

Framingham - Hyannis - Worcester

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