

Coming of Age

IN MASSACHUSETTS

A LEGAL RESOURCE GUIDE | 7TH EDITION

*A legal guide for individuals with
intellectual and developmental
disabilities and their families on
transitioning to adult services*

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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. These decisions require that you have reliable and up-to-date information. After all, our decisions are dependent on our having the right facts as applied to our individual situation. What may be appropriate for one person does not necessarily work for others. The purpose of this legal guide is to provide you with information about the journey that should help make your decisions informed ones that are appropriate for your situation. Hopefully, you will find it helpful whether adult services are years away or the transition is imminent.

In the following pages, you will find information about the legal consequences of turning 18 years old; important benefits from the state and federal governments; options for assistance with personal, financial and health care decision-making; and the importance of special needs planning by parents and other family members.

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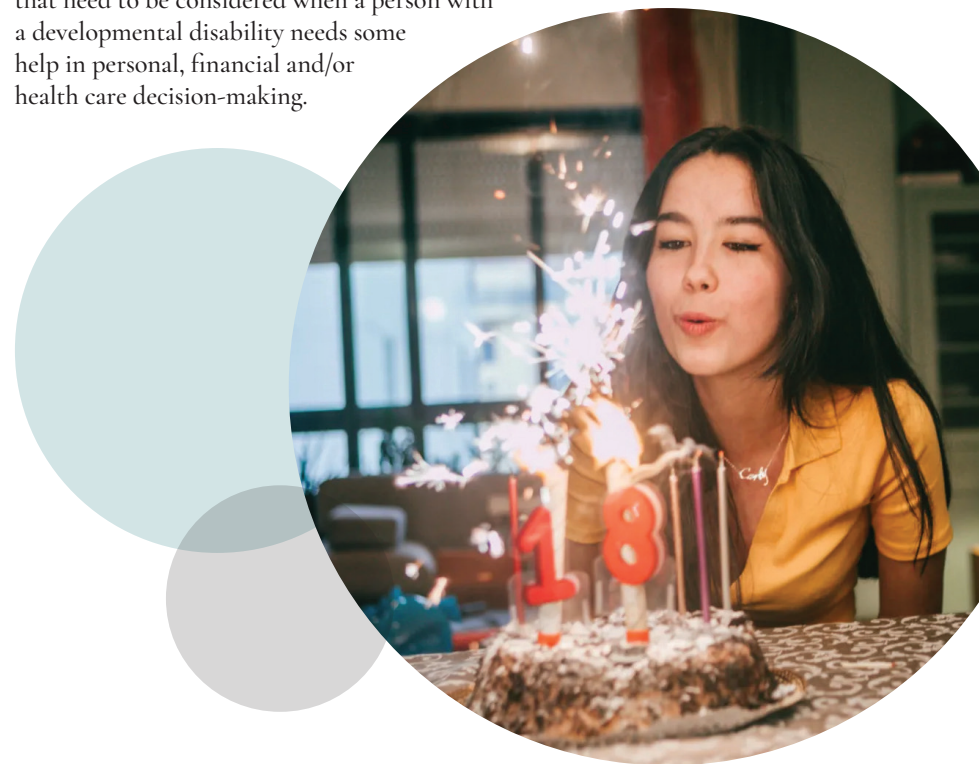
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LEGAL EMANCIPATION & TURNING 18

When a person turns 18 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 18, parents are no longer able to make decisions on their son's or daughter's behalf. This may seem counter-intuitive to some. I've had many parents tell me they thought that they retained decision-making ability by virtue of being either the biological or adoptive parent. This is clearly not the case. Importantly, emancipation means that, in most circumstances, parents are not entitled to receive personal information about their son or daughter from health care providers, human services professionals, or providers of educational and other services.

Many people may require support to make the best decisions immediately upon turning 18 years old. In fact, most people can use some help in making informed decisions throughout their lifetime. In some cases, individuals may need protection from making really bad decisions that could result in financial loss, serious injury or worse. At the same time, persons with intellectual and developmental disabilities have a right to enjoy legal capacity on an equal basis with individuals who do not have a disability. 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

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 Social Security Disability Income ("SSDI") or Supplemental Security Income ("SSI"), to be sent directly to the bank for 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 the 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 to a permanent withdrawal order. Through the use of a custodial account, payment can be made for goods and services on a regular and/or an as-needed basis.

TRUSTS FOR MONEY MANAGEMENT, GOVERNMENT BENEFITS PLANNING AND CREDITOR PROTECTION

A trust is a legal arrangement where funds and other assets are transferred to a trustee for the benefit of an individual. The person for whom the trust assets are held is referred to as a beneficiary. Trusts for the benefit of a person who has a disability should be established with the help of a lawyer experienced in wills and 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 from MASS Health, SSI and other important means-tested government benefits. Trusts are also critical in preventing a person from being financially exploited and can, under many circumstances, offer protection from the reach of creditors. A trust is usually a far more appropriate alternative to conservatorship (see the discussion on conservatorship to follow).

REPRESENTATIVE PAYEE FOR GOVERNMENT BENEFITS

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 over only income from the particular checks for which he or she is payee. Representative payees for recipients of SSI 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.

SUPPORTED DECISION-MAKING ALTERNATIVES

Durable Power of Attorney for Property

A durable power of attorney ("DPOA") for property is useful when a person has a mild or moderate incapacity and is capable of choosing a trusted person to handle his/her money as well as assist in making important decisions or choices. The DPOA is a legal document in which a person termed "the Principal" gives another person, "the Attorney-in-Fact," the legal authority to handle his or her financial affairs. A DPOA is revocable. This means that the DPOA can be revoked at any time by the Principal. Also, the Principal who creates the DPOA retains decision-making authority over his or her property. A benefit of a DPOA is that it is a flexible arrangement for a person who needs 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 the Attorney-in-Fact at a time when he or she is needed the most. A DPOA is also useful in case the Principal becomes incapacitated in the future. If a DPOA has been created prior to the Principal's incapacity, the Attorney-in-Fact can continue to act on behalf of the Principal without having to petition the Probate and Family Court to become a guardian. This is particularly relevant in certain situations when a subsequent decline in capacity is statistically likely. For example, recent medical research suggests that there is a high co-morbidity between Down syndrome and early onset of Alzheimer's disease. If Alzheimer's Disease does develop in later years, a properly drafted and executed DPOA will alleviate the need for a future guardianship proceeding.

Appointment of an Advocate

Individuals 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. This legal arrangement is similar to a DPOA except that the authority of the advocate is limited to specified areas.

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 the power. 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. If the Principal regains capacity to make or communicate health care decisions, then the authority of the health care agent to make these decisions ends. I recommend that the Principal complete a companion document that describes the personal preferences

of the Principal in the event there is no hope of recovery and if, in the opinion of the attending physician, the Principal will die and life-sustaining treatment will merely prolong the dying process.

HIPAA Release

Under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, personal health information (“PHI”) of an individual must be held in confidence by covered entities including health insurance companies, health care providers, hospitals and others who have access to PHI of that individual. Release of PHI must be done in writing with specificity as to the scope of the release as well as the duration the release is to be in effect. A HIPAA release provides a parent or trusted person access to PHI, which is essential if support is desired in the area of health care decision-making.

Informal Supported Decision-Making Arrangements

Increasingly, various informal methods of involving others in providing support around choice are being developed. A simple written declaration by an individual that she or he wants a particular person involved in providing support in one or more particular areas of her or his life can be relied on. The challenge in such informal arrangements is that the service provider, state agency or other third party may not acknowledge the legitimacy of such a declaration if such declaration doesn’t meet certain standards or criteria set administratively by such third party.

COURT APPOINTMENTS

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. 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 Massachusetts Uniform Probate Code 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 accounts and plans created by the conservators. As noted previously, if a competent person creates a DPOA, conservatorship can be avoided in most cases. In fact, I’ve often noted that a Conservatorship petition filed concerning a person who was previously competent represents a failure of proper planning.

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 or disability rather than incompetence. This incapacity or disability evidence focuses on functional limitations. A Clinical Team Report (“CTR”) must be filed with a guardianship petition for 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. A Medical Certificate (“MC”) must be filed with a guardianship petition for a person with a developmental disability who does not have an intellectual disability. There are important procedural distinctions between a CTR and an MC beyond the scope of this handbook. The CTR and MC assist the court in evaluating the need for guardianship. The Code favors limited guardianship rather than a full or all-encompassing guardianship. The Code also creates a requirement that guardians file a written report, called a Care Plan Report, 60 days from the date of appointment and annually thereafter. The Care Plan Report covers important areas of life such as living arrangements (including planned changes) and services. Also, the Code requires annual visits by the guardian, and there are requirements that the guardian must disclose and follow a health care proxy previously created by the individual. The guardian must follow the wishes as provided for in the health care proxy. The guardian cannot revoke the health care proxy without a court order.

Expanded Authority of a Guardian – Psychotropic Medication Administration and Extraordinary Medical Treatment



A guardian does not have inherent authority to consent to the administration of psychotropic medication (see Table of

Psychotropic Medication on pg. 26). In order to obtain this authority, the guardian must specifically request that his/her authority be expanded to include the ability to consent to the administration of psychotropic medications

that are listed in a treatment plan filed with the court. Such a treatment plan must be accompanied by a physician’s affidavit detailing the purposes, prognosis, risks, benefits, side effects, alternative treatment options and other relevant evidence. The incapacitated person must have an attorney appointed to represent him/her in the proceeding, including at the hearing. This procedure is commonly referred to as a “Roger’s procedure,” which refers to the landmark case establishing right to counsel in such cases. This type of proceeding is also required for extraordinary medical procedures. There is no clear legal rule that separates ordinary medical procedures from extraordinary medical procedures. A fairly straightforward dividing line used by some practitioners and judges is whether the procedure is life threatening, or experimental. When in doubt as to whether a particular procedure requires expanded authority through court action, a guardian would be well advised to seek the advice of an experienced attorney in this area.

As you can see, there are a number of options for personal, financial and health care decision-making. The best practice is to explore the least-restrictive options before moving toward more-restrictive options. In this way, 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.



LEGAL CAPACITY TO SIGN LEGAL DOCUMENTS

There is a presumption that all persons, regardless of disability, are legally competent. At times, a question may arise as to whether someone has the mental capacity to understand and provide informed consent in entering into supported decision-making arrangements. It is sometimes helpful to seek the advice of a qualified mental health professional, preferably at the doctorate level, in determining whether someone has the requisite capacity to execute supported decision-making documents. If you anticipate that a question may arise upon a person reaching the age of emancipation, it makes good sense to have this evaluation completed sometime between ages 16 and 17½.

DON'T FORGET TO REGISTER WITH THE SELECTIVE SERVICE

All male U.S. citizens who are 18 through 25 years of age must register with the Selective Service. Men with a disability who are not continually confined to home, a hospital or an institution must register. Even if a disability would disqualify a man from military service, he still must register with the Selective Service. Selective Service does not presently have authority to classify men, so even men with an obvious disability must register now, and if necessary, classifications would be determined later.



TRANSITION TO FEDERAL GOVERNMENT BENEFITS

GOVERNMENT BENEFITS BASED ON FINANCIAL NEED

Two important programs for persons with disabilities are SSI and Medicaid. In Massachusetts, Medicaid is referred to as MassHealth. Upon attaining the age of 18, individuals are eligible for SSI and Medicaid even if they are living with their parents, without the parents' assets and income being deemed as theirs. SSI provides a minimum monthly benefit payment, which varies based on living arrangement and income. In Massachusetts, SSI eligibility automatically entitles the SSI recipient to MassHealth. MassHealth eligibility is critical for access to a range of adult services and supports that can have a value far in excess of the SSI monthly benefit. Given the range of services that are presently available through MassHealth, it is important to be aware of the financial eligibility criteria to qualify for these two programs.

ELIGIBILITY FOR SSI

Eligibility for SSI requires that the person be aged, blind or disabled and that the individual have limited income and resources according to the guidelines of the program. 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. Since SSI is a welfare, needs-based program, there are significant impacts on the SSI monthly benefit based on the SSI beneficiary's receipt of earned and unearned income. A complete description of the impact of earned and unearned income is beyond the scope of this writing. You can learn more about the impact of earned income and unearned income by referring to the articles found on FletcherTilton.com.

IMPACT OF CHILD SUPPORT PAYMENTS ON SUPPLEMENTAL SECURITY INCOME FINANCIAL ELIGIBILITY

Child support payments made to a custodial parent on behalf of an adult son or daughter will be counted by the Social Security Administration as unearned income received by the SSI applicant. This will reduce and, in some instances, eliminate SSI eligibility. To avoid this result, it is necessary to obtain an irrevocable court-ordered assignment of the child support allocable to the SSI applicant to a special needs trust that meets the requirements of 42 U.S.C. 1396p. This is best handled prior to the



application for SSI. However, in my experience, most divorce lawyers don't consider, or even have awareness of, the impact that child support payments have on SSI eligibility. In cases where no analysis was done during the divorce proceeding, it's necessary to petition the Probate Court to modify the parties' Child Support Order to obtain an irrevocable assignment of the child support payments to a special needs trust meeting the requirements of 42 U.S.C. 1396p.

ACHIEVING A BETTER LIFE EXPERIENCE ACCOUNTS (ABLE ACCOUNTS)

ABLE accounts are not considered countable resources for purposes of the \$2,000 resource limitation under SSI and MassHealth. There are, however, significant limitations and other factors that should be fully understood before establishing an ABLE account. In 2017, Massachusetts enacted legislation enabling ABLE accounts to be established in Massachusetts. An ABLE account provides tax-free growth of account assets. Any person can make non-tax deductible contributions into the account. The income earned on the account is not taxed, and qualified disability-related expenses paid from the ABLE account are not taxable. ABLE account beneficiaries can have only one ABLE account. Total annual contributions to the account are limited to the annual federal gift tax exclusion limit, which is, as of this writing, \$19,000. You can roll over funds from a first party Special Needs Trust, a Pooled Trust, or a 529 College Savings Account. An additional \$15,560 of earned income can be deposited into the ABLE account.

There are other important eligibility criteria. The ABLE account must be for an individual who has been determined to have a disability prior to age 26. This can be demonstrated by a finding that the individual is eligible for SSI or SSDI. There is also an option to have a written medical statement provided on behalf of an individual who is not receiving SSI or SSDI but who does meet the definition of disability required for eligibility for an ABLE account. Once an account is established for an eligible beneficiary, distributions may be made for qualified disability-related expenses, which include education, housing, transportation, employment training

and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, and funeral/burial expenses. Distributions that are not disability related will be subject to income tax on that portion attributed to earnings from the account, as well as a 10% penalty. Under current rules, in order to open an ABLE Account, the age of onset for a person's disability is prior to age 26. Effective January 1, 2026, the age of onset will increase to prior to age 46. This will expand the number of persons who have a disability to take advantage of this relatively new savings option.

In order to maintain SSI eligibility, the ABLE account may not exceed \$100,000. However, the maximum amount that may be in an ABLE account in Massachusetts is \$500,000. If the ABLE account exceeds \$100,000, SSI monthly benefit payments will be suspended for as long as the account is over this amount. Once the account drops below \$100,000, SSI will be reinstated without the need for reapplication. There is no asset limit in ABLE accounts for Medicaid eligibility, regardless of the suspension of SSI benefits.

It is critical to understand that upon the death of the ABLE account beneficiary, any remaining funds in the ABLE account will be required to reimburse MassHealth for the value of the MassHealth benefits that had been provided to the beneficiary after the creation of the ABLE account. This differs from a third-party special needs trust, which allows for family members or other remainder beneficiaries to receive the unused funds. Although these new ABLE accounts will allow for more choice and opportunities to have access to money, careful and thoughtful analysis should be applied to all estate planning options so the most beneficial to each person can be selected.

FEDERAL BENEFITS NOT BASED ON FINANCIAL NEED

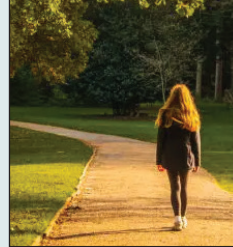
The major income and insurance programs in this category are SSDI and Medicare. A son or daughter (and, in some situations, a stepchild or grandchild) who meets the federal definition of disability and is receiving Social Security benefits is eligible to collect monthly cash benefits based on the parents' (or stepparents' or grandparents', if eligible) earnings previously paid into Social Security, provided that the child's disability began before the age of 22 and he or she is unmarried and is dependent for support on the parent who is retired, disabled or deceased. The monthly dependent benefit check is equal to 50% of the primary insurance amount ("PIA") of the covered worker while he or she is collecting due to disability or retirement. The monthly dependent benefit check increases to 75% of the PIA upon the death of the covered worker.

Disability is defined as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

A person who receives Social Security disability benefits for 24 consecutive months is entitled to Medicare. One advantage of Social Security benefits is that the benefits are not reduced or affected by the person's assets.

MILITARY PENSION BENEFITS

An important benefit for adult children with a disability of persons eligible for military pension benefits is that they now can have their parent's military pension benefits continue on for their benefit upon the death of the parent. Under the Military Pension Benefits Act, military families can protect the survivor benefit by allowing it to be directed to a qualified special needs trust for the benefit of the son or daughter with a disability. This election must be done with the Defense Finance and Accounting Service of the Department of Defense. The filing must indicate that the son or daughter is incapable of self-support because of a physical or mental incapacity. The filing must also include a certification from an attorney that the qualified special needs trust meets the requirements of Section 1917(d)(4)(a) of the Social Security Act, which requires a payback provision of trust assets upon the death of the trust beneficiary.



TRANSITION TO ADULT HUMAN SERVICE SUPPORT SYSTEMS

Special education entitlement in Massachusetts ends when the student turns 22 years old. Planning for the transition from special education entitlement to the adult human services support system should begin years before the 22nd birthday.

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 services 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 or 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 services agency might best meet the student's needs as an adult, and sends the referral directly to that agency. If a 688 referral has not been made but a student or parent feels that one should have been, he or she 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 two 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 (see the following).

IF A STUDENT IS ALREADY KNOWN TO DDS, IS A 688 REFERRAL STILL NECESSARY?

YES. Even though some individuals with intellectual disabilities 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 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 for 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 for assisting 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 aged 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 the student’s graduation and transition into adult supports, his or her case will be transferred to an Adult Service Coordinator within the Area Office.

WHO IS ELIGIBLE FOR SUPPORTS FROM DDS?

Intellectual Disability: A person 18 years of age or older with an intellectual disability is eligible for adult services from DDS. Intellectual disability means, consistent with the standard contained in the 11th Edition of the American Association on Intellectual and Developmental Disabilities: Definition, Classification and Systems of Supports (2011), significantly sub-average intellectual functioning existing concurrently with and related to significant limitations in adaptive functioning. As of this writing, DDS regulations state that intellectual disability occurs prior to age 18.

Developmental Disability: A person with a developmental disability is eligible for services from DDS. The legislative definition of a person with a developmental disability is an individual who is 5 years of age or older with a severe, chronic disability that (i) is attributable to a mental or physical impairment resulting from intellectual disability, autism, Smith-Magnis syndrome or Prader-Willi syndrome; (ii) manifests before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in three or more of the major life activities; and (v) reflects the need for lifelong or extended-duration services, assistance and supports that are individually planned and coordinated. Also, an individual meets the definition of a person with an intellectual disability if he or she is under the age of 5 and has a substantial developmental delay or specific congenital or acquired condition with a high probability that the condition will result in a developmental disability if services are not provided.

WHAT IS THE APPLICATION PROCESS?

Application Process: The application process is initiated by sending an application form (Application for DDS Eligibility) to the DDS Regional Eligibility Team. The DDS application is available online on the DDS website: www.mass.gov/cohhs/gov/departments/dds/. The application form requests basic information about the applicant

that enables a Regional Eligibility Specialist to contact 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 conversation.

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 another location. The intake process generally consists of the initial interview, the gathering of relevant information that 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 Department 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. A determination summary is provided explaining the denial of eligibility.

PRIORITIZATION AND 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 the Massachusetts Comprehensive Assessment Profile (“MASSCAP”). MASSCAP is a clinical assessment tool that determines the need for a particular service. 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 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 from zero to three points, with zero points meaning never or rarely does well in that area, and three meaning does very well in that area. This information is then entered into the ICAP application to determine the total ICAP score.

Another tool of MASSCAP is the Consumer and Caregiver Assessment (“CCA”). CCA allows DDS to analyze the resources and supports that are currently in place for the individual, provide 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. CCA looks at the current caregiver and his or her ability to continue to provide support in a manner that keeps the individual safe from harm.

A 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 functional behavioral tests that may better define an individual’s need. The decision to include additional assessments is strictly at the Department’s discretion.

Once 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 needs into three groups: Priority 1, Priority 2 and No Priority. 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. This time period, however, is dependent on funding. A No Priority determination means that services are not considered a priority for funding by DDS.

PRIORITIZATION OF SERVICES FOR PERSONS WITH A DEVELOPMENTAL DISABILITY

The Supports Intensity Scale (“SIS”), which has been developed by the American Association on Intellectual and Developmental Disabilities (“AAIDD”), is utilized by the Department of Developmental Services in assessing the support needs of individuals found eligible for DDS adult services as persons with a developmental disability. SIS helps determine the supports necessary for someone to succeed. A full description of SIS is beyond the scope of this writing. You can learn more about SIS and AAIDD at www.aaidd.org.

Appeals

Individuals have the right to appeal any findings contained in the eligibility or prioritization letter within 30 days of receiving the letter, and have the right to a Fair Hearing before an impartial hearing officer. While a Fair Hearing is administered under the Informal Rules of the Administrative Procedures Act, it is strongly encouraged that counsel be retained for the proceedings.

Adult Family Care – An Option for Families

Persons with a disability aged 16 years or older are eligible for Adult Family Care (“AFC”). This program permits a family member, often a parent, to be a paid caregiver to another family member with a disability who needs assistance in performing certain basic activities of daily living. An important requirement for paid care providers is that they may not be legally responsible for the person to whom they are providing care. In the case of a parent, they must be providing care to an emancipated son or daughter for whom they are not guardian. There are two levels of care depending on the degree of support the individual needs. Caregivers are paid a salary, receive support and training from the Adult Family Care provider agency, and receive home visits from a social worker and a nurse, and receive respite. Compensation paid to AFC providers is exempt from federal and state income tax.

Real Lives Legislation – Right to Self-Determination

Under this legislation, DDS is required to offer self-determination as an option to all individuals eligible to receive services. DDS is also required to facilitate and assist in the development of a person-centered plan, individual support plan and individual budget for each participant. Most importantly, DDS is mandated to ensure that the value of a participant’s budget is equivalent to the amount DDS would have spent providing services, supports or goods to the participant if the participant had chosen to receive those services, supports and goods through a traditional service model. Admittedly, this process will take some time to evolve as experience develops around how to move funding to an individually driven and funded support plan. This process should empower individuals and their families to leverage funding to create a life that is individually relevant and empowered.

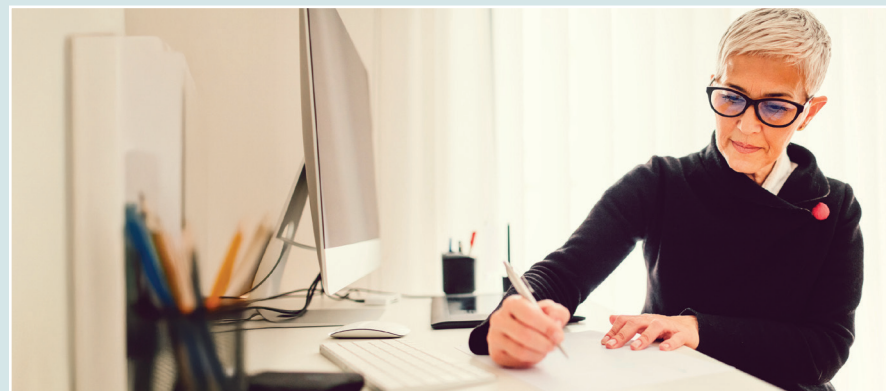


SPECIAL NEEDS ESTATE PLANNING BY PARENTS

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 need to realize that without careful planning, an inheritance may make their child ineligible for benefits that can be far more valuable than the inheritance. In some cases, the more a person inherits, the worse off he or she may be. Government benefits are important because it is seldom possible for the average family to leave sufficient funds to provide the necessary services and supports. 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 20 or 30 years from now.

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 supplemental needs trust, also called a special needs trust, which holds assets for the benefit of a person and 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 supplemental needs trust funded by the beneficiary’s family are distributed to those persons identified in the trust, and not to the government.

Beyond maximizing eligibility for government benefits, special needs estate planning also recognizes the vulnerability of many individuals with intellectual and developmental disabilities to financial exploitation. A properly drawn and administered supplemental needs trust prevents financial exploitation and ensures that trust assets are used to promote a high-quality lifestyle for the beneficiary.





IMPLICATIONS FOR FAMILIES REGARDING SPECIAL NEEDS PLANNING

Special needs trust expenditures can include but are not limited to:

- Additional physician visits (over the Medicaid limit)
- Appliances
- Bicycle, fitness equipment and personal trainer
- Bottled water
- Bus or train pass
- Cab scrip
- Cable TV bill
- Car/van: fuel, repairs, maintenance and insurance
- Cell phone
- Club dues
- Computer, Internet service, software, training and repairs
- Curtains, blinds and drapes
- Dental work, eyeglasses and 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
- Housecleaning/maid service
- Incontinence supplies and equipment
- Laundry/dry cleaning
- Legal fees/guardian fees
- Lessons, classes, or college tuition and fees
- Linen
- Massage, acupuncture/acupressure, Rolfing and other alternative treatments
- Musical instruments
- Nonfood grocery items such as laundry soap, bleach, tissues, household cleaning products, paper towels, napkins, deodorant, soap and 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 and 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 and radio
- Vacation
- Vitamins, and herbs
- Wheelchairs not covered by Medicaid, repairs and 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.



PREPARING A LIFE-PLANNING DOCUMENT FOR YOUR DISABLED FAMILY MEMBER

A life-planning document, sometimes called a “letter of intent” or “letter of instructions,” aims to provide critical information to future service providers and trustees.

Such a document can contain 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 will 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 life-planning document is important because many people with cognitive or psychological impairments may be unable to accurately convey pertinent facts and information about themselves to others. The life-planning document gives you an opportunity to communicate your perspective on and knowledge of your family member 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. Fletcher Tilton PC has developed a life-planning document template to help parents begin this process. This template can be found on our website, www.flechertilton.com. The initial effort can be considerable and daunting as you try to think of everything to include. Rest assured that updates are usually much easier. We recommend that you update the life-planning document at least once a year, perhaps around the birthday of your disabled family member. Using his or her birthday may help you remember that it is time to update the document. Time has a way of flying, and without a trigger date to help you remember, you may forget to update the plan.

If you find it difficult to write a life-planning document, we recommend that you work with a qualified person who can facilitate a discussion and help 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, rely on someone who can listen well to the story you tell and who can write it in coherent, understandable terms.



PLANNING A FUTURE HOME

10 CONSIDERATIONS

A growing number of parents have developed a residential setting for their son or daughter, ranging from a simple one-bedroom condominium setting, to an apartment with roommates, to a home with paid care providers. In working with these parents, I've compiled the following observations regarding these experiences:

1 | FUTURE OF GOVERNMENT RESOURCES

The future of domestic spending on programs that provide support to individuals with disabilities is uncertain. On the federal level, there will be continuing efforts to reduce the federal deficit. Individuals with disabilities, recipients of Medicaid benefits and others who rely on government assistance for health care will face the threat of reductions in appropriations, elimination of some benefits and a conversion to Medicaid block grants. These threats are real. So, in planning a future residence, there must be significant reliance on private funds. While we must continue to advocate to maintain and increase federal and state appropriations as well as work toward creating more cost-effective models to use government appropriations, families must not rely on the hope that government resources will be the sole support of their son or daughter in the future.

2 | IMPORTANCE OF STARTING EARLY WITH A PLAN

The parents who have successfully arranged an appropriate home for their son or daughter started the planning process one to three years before their son or daughter moved in. The reasons for planning early are self-evident. First, you need to develop consensus within the family about whether your plans make sense and to build an internally driven commitment within the family to keep moving forward. One very obvious trap is the Get-To-It trap. These are the ideas, plans and things that need to be investigated, performed and vetted in order to move forward, but you put them on your To-Do list. The problem is that many people never Get-To-It. These are the things that you'll get to ... someday. But the list grows and grows while life just happens. The late management consultant, Steven Covey, wrote about the critical importance of prioritizing those things in our lives that at the moment are not urgent but that are very important. The key is to differentiate those things that are truly urgent and important from the crisis of the day or week that seems urgent but is not, in reality, all that important. My advice is to schedule some quiet time on a regular basis to write out your thoughts, talk about your plans with your spouse and important other people, and conduct your due diligence. This can be an ongoing planning meeting for you and your family members, with invitations going out to others on an as-needed basis.

3 | THE USE OF LEVERAGE

Broadly speaking, leverage is creating more power through the creative use of resources. For instance, leverage can be three or four families coming together to pool their money to create more buying power so they can purchase a home more easily together than they could on their own. Some families may have more financial resources than others, while some may have more time to contribute. Don't minimize the value of time that can be contributed. In one successful model, two families planned an arrangement in which one family purchased a house next to the other family, who did not have the financial capital to contribute toward the purchase of the house. But the family without the available capital had something as valuable as money; they had human capital. They lived next door and provided support to the two young adults living there. It worked. Also, many retirement plans can be leveraged through a loan. Repayments must be made at a marketable interest rate, but remember, you're replenishing your own retirement account by paying down the loan. You will need to check with your retirement plan administrator to see if this is possible with your particular plan. Finally, you should evaluate the advisability of refinancing your principal residence or taking out a home equity loan.

4 | THINGS CHANGE – BE FLEXIBLE

Where we live depends on many factors, including the location of family and friends, our work, the type of environment we choose to live in, and a host of other considerations. Things change. We downsize, we retire, we get divorced, etc. And major life events are often accompanied by a change in living environment. In most circumstances, real property in a trust or in a corporate real estate holding entity can be exchanged with very little difficulty to accommodate changes in the location of property.

5 | IDENTIFY HOUSING DOLLARS SEPARATE FROM SUPPORT AND SERVICE DOLLARS

The acquisition and regular maintenance of real estate can be budgeted and planned for in a fairly easy fashion. The source of funds to purchase may come from savings, a loan from a retirement account, a gift from family members, proceeds from a home equity loan, etc. The regular carrying cost of the home can be paid from anticipated rental income, a planned escrow account or other anticipated revenue. Consider creating an annual budget for estimated housing costs as a planning tool. Two important sources of government funding for residential support for individuals with disabilities are the Section 8 voucher program and, in Massachusetts, the Alternate Housing Voucher Program ("AHVP"). Both programs are administered through housing assistance agencies and local housing authorities. Applications for rental vouchers can be obtained and filed at local housing authorities. Even though a long waiting list should be anticipated, an application should be filed if there is a tangible possibility of your son or daughter moving out of your home. Under federal regulations governing the use and administration of Section 8 housing vouchers, a person with a disability who has been granted a voucher is entitled to a reasonable accommodation in how the voucher is used. This means that the customary "arm's-

length” requirements between landlord and tenant can be modified. So a family-owned or family-controlled rental unit can be leased to a family member with a disability who has a voucher. In some circumstances, a special needs trust can be the landlord and the beneficiary of the trust can be the tenant.

6 | KNOW THE SUPPORT AND SERVICE NEEDS OF INDIVIDUALS

A complete understanding of the service and support needs of each individual must be arrived at as part of the planning process. While this may seem obvious, there is one general tendency I’ve noticed over the years. Parents often overestimate their son’s or daughter’s daily living skills. Often, parents discount the value of a regular routine, the presence of familiar family members, and the often overlooked presence of verbal and nonverbal cueing that is natural in a home environment. It may be a worthwhile expense to retain the services of a qualified professional to assist you in accurately evaluating the level of services and supports your son or daughter as well as other prospective residents will need when they move into their new home. Accurately assessing the service and support needs of each individual is essential in estimating the anticipated costs of meeting those needs through appropriate staffing.

7 | IDENTIFY SUPPORT AND SERVICE DOLLARS

Obviously, if your son or daughter and other prospective residents are eligible for adult services from a state agency, you should speak with the appropriate person assigned to his or her case about your intentions. This person can be helpful in providing a realistic expectation about prioritization and allocation of resources. Also, personal care assistance (“PCA”) funded through the Division of Medical Assistance can be a source of support dollars. A determination of whether PCA is appropriate and the extent of the PCA support should be made as soon as possible. Finally, each resident’s SSI, Disabled Adult Child (“DAC”) benefits and other recurrent monthly income will be available to fund a portion of the supports to be provided. It is customary that 75% of the recurrent monthly income of each resident be paid in the form of a service fee. Also, for many families, privately paying for services and supports has become a daunting but necessary reality.

8 | IMPORTANCE OF GOOD ADVISORS

The activities of maintaining a home for a son or daughter with a disability can involve, for instance, the purchase of real estate, creating a landlord/tenant relationship, having service and supports provided on a regular basis by paid staff, maintenance and upkeep, etc. An attorney should be involved in many of these areas, including selecting the appropriate legal entity to own the real estate, creating a sensible service agreement for settings that are non-DDS or non-DMH regulated, understanding and complying with applicable labor/employment practices, and identifying potential sources of liability and taking steps to minimize and/or avoid such liability. The skills and talents of experienced staff who can manage a residential setting can be a valuable asset. A



number of highly skilled administrators with years of experience managing residential services and supports for individuals with disabilities are available to serve on either a short-term consulting or long-term management fee basis. You don’t have to reinvent the wheel! Of course, having a reliable handyman, plumber and electrician on speed-dial can save time and lower your blood pressure when the inevitable, yet unexpected, housekeeping crisis hits.

9 | INTEGRATION OF THE HOUSING MODEL INTO YOUR ESTATE PLAN

You must plan for how the home will be managed when you are unable to be involved due to age, death or disability. A comprehensive special needs plan is an essential part of developing a home for your son or daughter with a disability. The fundamental documents must provide for the distribution of assets to the appropriate persons and trusts in the proportions desired. Durable powers of attorney with critical Medicaid planning language and health care proxies are essential. The use of a special needs trust to hold assets for the benefit of a son or daughter with a disability to pay for future services and supports is the centerpiece of this plan. These essential documents must be coupled with a realistic financial plan adequate to provide for supplemental services and supports throughout the lifetime of a son or daughter with a disability.

10 | IMPORTANT PERSONAL QUALITIES: PATIENCE AND PERSISTENCE

There is no cookie-cutter approach to developing an effective and successful residence plan for your son or daughter with a disability. It is easy to get disillusioned because solutions are slow to develop. There are many moving parts and some dead ends. The parents I’ve had the privilege to work with in these types of situations have demonstrated an enormous amount of patience and persistence. They share a common characteristic of expecting more from themselves than from anyone else, including the government. There is also a sense of “I know best” and “I’m going to keep trying.” These personal characteristics of patience and persistence imbued with a sense of optimism are important for a successful move from the vision of a home to a real home.

Below is the chart of psychotropic medications referenced on page 7.

LIST OF COMMON PSYCHOTROPIC MEDICATIONS	
TRADE NAME	GENERIC NAME
Abilify	aripiprazole
Clozaril	clozapine
Etrafon / Triavil / Triptafen	perphenazine + amitriptyline
FazaClo ODT	clozapine
Fanapt	iloperidone
Geodon	ziprasidone
Haldol / Haldol Decanoate	haloperidol / haloperidol decanoate
Invega / Invega Sustenna	paliperidone
Latuda	lurasidone
Loxitane	loxapine
Mellaril	thioridazine
Moban / Lidone	molindone
Navane	thiothixene (tiotixene)
Orap	pimozide
Prolixin	fluphenazine
Prolixin Decanoate	fluphenazine decanoate
Rexulti	brexpiprazole
Risperdal / Risperdal Consta	risperidone
Saphris	asenapine
Serentil	mesoridazine
Seroquel / Seroquel XR	quetiapine
Stelazine	trifluoperazine
Stemetil / Buccastem	prochlorperazine
Taractan	chlorprothixene
Thorazine	chlorpromazine
Tindal	acetophenazine
Trilafon	perphenazine
Vesprin	trifluopromazine
Vraylar	cariprazine
Symbyax	olanzapine + fluoxetine
Zyprexa	olanzapine
Zyprexa Relprevv	olanzapine
Zyprexa Zydys	olanzapine



ABOUT THE AUTHOR

Frederick M. Misilo, Jr., is Chair of the Trust and Estate Department at Fletcher Tilton PC, a regional law firm with offices in Worcester, Boston, Framingham, Cape Cod and Providence, RI. He also serves on the firm's Management Committee.

Fred has over thirty-five years of experience in estate planning, estate administration, trust management, and asset protection. He specializes in complex succession planning, with extensive experience in special needs and elder law. He is admitted to practice in Massachusetts, Rhode Island, and Florida, and holds the designation of Certified Trust and Fiduciary Advisor (CTFA).

Attorney Misilo serves as Chair of the Board of Directors for Fallon Health, a Massachusetts-based nonprofit, community-focused health insurance company, as well as for The Arc US Foundation, a Washington, D.C.-based nonprofit that advances the mission of The Arc of the United States—the nation's largest and oldest civil and human rights organization supporting individuals with intellectual and developmental disabilities. His leadership roles include Past President of both The Arc of the United States and The Arc of Massachusetts, as well as former Chair of the Worcester Regional Chamber of Commerce. He served three terms on the Holden Board of Selectmen, including three years as Chair. In state government, he served as Deputy Commissioner for the Massachusetts Department of Developmental Services during the Weld administration. Earlier in his career, Fred was Executive Director of Harbor Area Community Services, Inc., a Boston-based organization providing residential support to individuals with intellectual and developmental disabilities.

Attorney Misilo was inducted to the *Massachusetts Lawyers Weekly* Hall of Fame in 2025; received the Key to the City of Worcester in 2025 for his lifelong contributions to advancing the interests of persons with disabilities, seniors, and others to promote their dignity and quality of life through legal advocacy; was honored as Riverview School's 2024 Dream Maker; received a Lifetime Achievement Award in 2023 by ALM and Law.com; received the 2011 Joseph Andrade Award for Leadership and the 2012 Rose Pessin Memorial Award from The Arc of Massachusetts; and The Arc of Cape Cod presented him with the Arc Angel of the Year Award in 2010. Attorney Misilo has been listed in the *Best Lawyers in America*® yearly since 2012.

Attorney Misilo provided technical assistance, and his advocacy work was featured in *Autism: Coming of Age*, a PBS documentary that addressed the challenges faced by individuals with autism and their families. This documentary was chosen by judges from CBS, NPR, ABC and the PBS News Hour as the 2012 winner of the National Journalism Award from the National Institute of Health Care Management.

We would also like to acknowledge and thank Attorney Theresa Varnet and Attorney Anne Grenier for their contributions in updating this 7th edition.

WE CAN HELP

The attorneys at Fletcher Tilton PC are experienced in representing clients with special needs issues. We have extensive experience with special needs estate planning, guardianships and other less restrictive measures, DDS eligibility appeals, ISP appeals, and 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 additional free information on the issues covered in this handbook, as well as helpful tools and articles, please visit our website:

FletcherTilton.com



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