

SPECIAL NEEDS ADVOCACY TOOLKIT

Steps to a Better Future



Prepared for the Special Needs Community by the Special Needs Subcommittee
of the Massachusetts Chapter of the National Academy of Elder Law Attorneys
www.MassNAELA.com

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INTRODUCTION

ad·vo·cate

noun

/ˈadvəkət/

1. a person who publicly supports or recommends
"he was an untiring advocate of economic reform"
synonyms: champion, upholder, supporter, backer,
spokeswoman, spokesperson, ca

WELCOME SPECIAL NEEDS ADVOCATE!

This booklet is offered as a resource, or "toolkit," to help you support and promote the rights and well-being of individuals with special needs.

Each chapter addresses a topic that impacts individuals with special needs. Special needs advocacy is important work and it is the aim of this toolkit to support, facilitate, and encourage that work.

ADVOCACY

Advocacy is the act of speaking on behalf of or in support of a cause or person. Advocacy by, or on behalf of a person with special needs is communication to ensure that a person's needs are being met.

GOALS

Advocacy seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- Be heard on issues that are important to them;
- Defend and safeguard their rights; and
- Influence decisions that affect their lives.

Advocacy is a process of supporting and enabling people to:

- Express their views and concerns;
- Access information and services;
- Defend and promote their rights and responsibilities; and
- Explore choices and options.

EFFECTIVE TYPES OF COMMUNICATION



LETTERS WRITING A LETTER IS A VERY PERSONAL WAY TO VOICE YOUR OPINIONS AND MAKE NEEDS KNOWN

E-MAIL E-MAIL IS A PRACTICAL AND EFFICIENT WAY TO STAY IN TOUCH WITH SERVICE PROVIDERS ON A REGULAR BASIS TO REACH THEM QUICKLY

SOCIAL MEDIA SOCIAL MEDIA CAN BE A GREAT METHOD TO SPREAD AWARENESS

TELEPHONE CALLS MADE ON A REGULAR BASIS WILL KEEP EVERYONE INFORMED ON THE PROGRESS OF PLANS AND HELP YOU STAY CONNECTED

FACE-TO-FACE CONTACT THESE MEETINGS PROVIDE INSTANT FEEDBACK AND CAN CREATE THAT PERSONAL CONNECTION

ADVOCACY TIPS

- BE INFORMED
- CHECK IN REGULARLY
- BE FRIENDLY
- FIND COMMON GROUND
- BE OPEN
- BE PREPARED
- DON'T GET SIDETRACKED
- BE CONCISE
- BE ORGANIZED
- DON'T BE AFRAID TO ADMIT YOU DON'T KNOW
- CREATE A TEAM
- DON'T GIVE UP

IT TAKES 5 MINUTES TO MAKE A PHONE CALL OR SEND AN E-MAIL THAT COULD IMPROVE THE LIFE OF A PERSON WITH SPECIAL NEEDS

HOW TO BE A GREAT ADVOCATE

For most families and disabled adults this advocacy journey is “a marathon, not a sprint.” The emphasis must be on taking care of yourself and your family in order to take on the long-term role of advocate. Don’t underestimate the value of getting some exercise, having a routine, eating well, laughing, taking deep breaths to relax, and surrounding yourself with positive people. This can be hard to do sometimes when facing so many challenges. Also, remember that each member of a family is important and should have his or her needs valued and met.

While important for anyone, these “little things” are actually critical for those who struggle to find a “normal” life while dealing with disability. These little things can also be the most difficult to obtain for any family affected by disability. Don’t get lost in the fight for disability services, school services or insurance coverage. Long-term stress from a conflict driven life can have a huge impact on the health of a caregiver.

1. SEPARATE THE URGENT FROM THE NON-URGENT ISSUES.

Write down goals and link those with appointments and tasks that are already set up.

2. GATHER INFORMATION.

Go on the web to search for information but limit your time online. Disability can be very isolating and there is a tendency with the isolation to be online for literally hours and hours to research everything that has ever been published. Research your current issues, but keep a balance. Try not to become overwhelmed.

Write a brief summary of the issue you are facing. It should be concise and without emotion. If a provider is open to it, share your summary in advance. If not, use it for your own notes and to prepare for upcoming meetings or communication.

3. BECOME THE EXPERT.

Most families and individuals with disabilities are going to interact with many professionals, caregivers, educators, clinicians, etc. in their lives. Typically, there is a team of people with different functions and expertise who work with a disabled individual and his or her family. There is not always an opportunity for each member of the team to consult with others on the team. In addition, team members do not always agree on goals or action steps. This puts you, the individual or advocate, right in the middle.

Document steps you have taken and results from those actions. If you have tried a certain therapy or medication and it did not have a great outcome, then write it down. If you have applied for a certain benefit in the past and were denied, document that as well.

When you work with the various members of your team, you will develop credibility if you are organized and can summarize issues quickly.

4. PULL TOGETHER A TRUSTED TEAM.

This will take some time. Many therapists, schools, and service providers will not be a good match the first time out. Even when you do find a good fit, people change jobs, an individual’s needs change and benefits rules change as well. It is an ever-changing landscape and hard to keep up. However, knowing that plans may change, a great advocate will always have a plan. Find the best team for your current plan.

Here is an example: An advocate with a very medically fragile child was working with a case manager from the Department of Developmental Services to receive children's services. That case manager kept bringing her own healthy child to the family's home for her case management visits. The advocate was so distraught by this that it completely interfered with her focus on service planning. The advocate called a supervisor and expressed her concern about the situation. The case manager was new in that role and did not realize the impact her own child's presence was having on the meeting. The problem was fixed and ultimately that case manager became a valued member of the disabled child's team.

5. LEARN TO PRIORITIZE.

Once you have your goals listed, team organized, and have done your research, now you can prioritize an action plan to address and advocate for certain issues. You do not have to deal with all the issues all the time. It is likely that very few decisions actually have to be made immediately.

6. BE ASSERTIVE – NOT OVERLY AGGRESSIVE.

Advocates need to be assertive to obtain benefits that meet the needs of most disabled individuals and their families. Providers often do not agree, sometimes do not respond, and sometimes do not do what you need to have done in a timely manner. Assertiveness can mean getting better results or outcomes because that means you actually go after what you need. Many providers are underfunded, understaffed, and in general, just overwhelmed with all the individuals they are meant to care for.

Be mindful of your emotions. When advocates become frustrated, assertiveness can become abusive and this abuse is often misdirected. It is understandable that families and individuals get frustrated, but be cautious. These same people who frustrate you now are the ones who ultimately will be there to help you. In fact, even if they are underperforming, they may be all you will get to assist you in any given area.

Unfortunately, sometimes even advocates with the best intentions can bring negative attention to themselves or their family. Because you are the hub of the team, you become the central source, or "gatekeeper", of all information. It may not always be possible to have the team speak to each other in a group format. Therefore, your communication must be precise, with as little emotion as possible, and succinctly documented.

For example, if you are having difficulty in your child's group home, keep a journal and bring it with you to team meetings and medical appointments. If you write things down when they happen, it will carry more weight as a source of information.

7. SHARE THE ADVOCATE ROLE!

You may not see the immediate value in the team you have assembled - the therapists, teachers, service providers, social workers, nurses, doctors, and lawyers. But it is very important that there are many people who know you and your family and feel invested in the care of the disabled person. Once you find someone who is a strong and willing advocate for the disabled individual, enlist him or her and thank him or her for his or her assistance. Stay connected so that you can enlist the help of these individuals as circumstances change.

8. GET HELP WHEN CONFLICT ARISES.

- a. Gather your supports: outside or second opinions can be very helpful when conflict arises.
- b. Gather documentation: bring your journal, test results, clinic visit notes, teacher observations, medicine administration journals and any other documentation that could prove helpful.
- c. Watch your communication: people under this type of stress may not think clearly and may not understand all the proceedings. You may want to lash out and be very aggressive. However, maintaining civility and calm is of utmost importance when conflict arises.
- d. Get a lawyer: finding a lawyer who knows his or her way around your legal issue is key. Under some circumstances, the disabled person or their family member may be entitled to free legal counsel. Do not sign anything, or in some cases, continue to make statements, until you have consulted with counsel. Once your statements are on the record, it is difficult to unwind them if they are not accurate

9. MAKE YOUR MEETING PRODUCTIVE BY ORGANIZING YOUR RECORDS.

Use a multi-section notebook and keep separate sections of notes on telephone calls, contacts, medical concerns, and legal issues. Have a to-do list for each member of the team with action steps and the results you want to see. At the end of every meeting, set a specific date and time for the next meeting. Follow-up with emails if necessary.

10. NURTURE RELATIONSHIPS.

Finally, be thoughtful about the long-term value of developing relationships with physicians, providers, schools, case workers and others. Nurture these relationships. Of course, you have legal rights, but remember, these rights are moderated by people. It is always better if plans are a team decision rather than a reluctant response to a demand. Give the team the benefit of the doubt and believe that everyone is working hard and trying their best. The saying you “catch more flies with honey than with vinegar” requires patience and a thoughtful approach by the person who is in the role of advocate. Some individuals or advocates see this approach as “giving up,” and feel that if they are not “fighting” for better care then they will be defeated. In fact, the advocate who is an active and valuable part of a team is a true leader and likely to be more successful than an overly aggressive or adversarial one in getting the best possible care and outcomes. Being patient, thoughtful, and encouraging in relationships with people and healthcare providers (who are often the source of frustration and bad news!) is a challenge but critically important.

FIVE KEY STEPS TO EFFECTIVE ADVOCACY

1 KNOW YOUR OPPONENT

Who has the authority to give you what you need?

Special Education Director vs. Team Leader

Agency Case Worker vs. Director

Insurance Company

What is the policy/procedure in the given situation?

Read the policy manual

Know the rules

What is the personality you are dealing with?

How do they usually respond to similar requests?

How familiar are they with their own rules and regulations?

Do they have specialized knowledge in this area?

Do you have anything in common with them?

2 BE AN EXPERT IN YOUR FIELD

Know what you are asking for

A new technique

A certain piece of equipment

A diagnosis

Have the research handy

Let the experts make your case

Do demonstrations

Take pictures

3 BE CREATIVE

You have all the answers!

Craft a solution right

from the beginning

Work backwards from there

Keep it simple

Use visuals if you can

4 COMMUNICATE EFFICIENTLY

Take the emotion out of it

(unless you know that works
with your opponent)

Be clear

Be concise

Practice if you need to

Use written tools to assist you

5 BE PREPARED TO...

Compromise

Lose some

Be upset (behind the scenes)

Be patient

Your timelines are yours

(not anyone else's)

It took you a long time to learn too!

EDUCATIONAL ADVOCACY



In the United States, all children are entitled to a free and appropriate public elementary and secondary education. This section of the toolkit provides an overview of services available for disabled children between the ages of 0-21 years.

EARLY INTERVENTION (AGES 0-3)

States must implement a statewide system of services for infants and toddlers, birth to age three, with developmental delays or disabilities, and their families. To determine if such services are necessary, there must be a timely evaluation of the functioning of each infant or toddler with a disability. Following the evaluation, the state must develop an individualized family service plan, commonly referred to as an Individualized Family Service Plan (IFSP), to describe the services that are needed by the child and family and how they will be implemented. Early intervention services are funded, in part, with state and federal funds.

In Massachusetts, a child is considered eligible for early intervention services if he or she is under the age of three and for whom there are developmental concerns due to an identified disability or whose typical development is at risk due to certain birth or environmental concerns.

Services are to be comprehensive, integrated, and individualized, utilizing a family-centered approach and facilitate the developmental progress of eligible children. Services may include but are not limited to: assistive technology, audiology services, health services (clean intermittent catheterization, tracheotomy care, g-tube feeding, the changing of dressings or colostomy collection bags, and consultation with service providers concerning special health care needs), medical services (diagnostic or evaluation services by a licensed physician to determine a child's developmental status and the need for early intervention services), nursing services, and nutrition. Other services may include: occupational therapy, physical therapy, speech/language pathology, vision services (evaluation and assessment of vision, referral for medical or other professional services necessary for the habilitation or rehabilitation of visual functions), psychological services, and social work services.

Anyone (a parent, doctor, caregiver, teacher or friend) can refer a child to a certified Early Intervention program. To find a listing of programs by location call 1-800-905-8437 or visit the Family TIES of Massachusetts website at www.massfamilyties.org/ei/eicity.php.

EDUCATIONAL ENTITLEMENTS (AGES 3-21)

Children between the ages of 3 and 21 with disabilities severe enough to negatively affect learning are entitled to special education services at no cost to parents. These services are federally mandated in all states. In most states, it is the responsibility of local school districts, with oversight provided by the State's Department of Education or its equivalent governmental office.

School districts are responsible for identifying, evaluating, and then classifying children with disabilities as eligible for special education and related services. State regulations set out time lines and the methods to accomplish this, as well as administrative procedures to resolve any disputes.

Federal law requires that each child must receive a program that meets his or her unique and individual needs. School districts must annually develop a written Individualized Education Program (IEP) that outlines the services to be provided with measurable goals. For some children, the IEP might involve classroom modifications, individual instruction or therapy. Other children might require placement in a specialized class or placement in a private school, that specializes in serving children with a particular type of disability. Private schools can provide services on a day or a residential basis. Depending on need, children might be entitled to additional educational services over the summer months.

Children may be eligible for 'related services' as part of their IEP. Related services may include speech therapy, occupational therapy, physical therapy, and school-based nursing services.

Schools must document a child's special education needs as well as his or her progress in school. Evaluations and other records can be helpful later in life to determine eligibility for adult services and other government assistance programs.

To connect with other parents and caregivers of special education students in your school district, contact the local SEPAC (Special Education Parent Advisory Council). Connections with other parents and caregivers is a valuable way to build community, share resources, and obtain support and advice from other similarly situated people.



MEDICAL ADVOCACY FOR PERSONS OVER THE AGE OF 18

Many parents do not realize that when a child turns 18, the parents stop being the child's guardian and may no longer be able to receive information from the health care team about their child. If a person you are advocating for is 18 or older, you need legal authority to speak on the person's behalf and access his or her private health related information.

GUARDIANSHIP

In the eyes of the law, even an individual with a significant developmental disability is legally permitted to make decisions on his or her own behalf at the age of 18. Therefore, if due to a disability, a person is not capable of making his or her own decision, it is necessary to secure the judicial appointment of a guardian. There is no assumption of incapacity even in the most obvious of cases. In Massachusetts, only a judge in your county Probate and Family Courts can declare someone incapacitated.

A guardian is a person who has been appointed by the Probate and Family Court to make personal and medical decisions on behalf of the individual who has been deemed incompetent. The guardian's job is to make day-to-day decisions regarding support, care, education, health, and welfare. The guardian does not bear any risk for the person's acts or debts, and is under no legal obligation to provide a home or direct care to the person. There are ongoing reporting requirements to the court.

Since the Probate and Family Court handles legal guardianship proceedings, you may want to seek out an attorney with experience in handling guardianships to guide you through the process. In some circumstances, an attorney will be appointed to represent the incapacitated person. In this case, it may be more important that you, as the petitioner, are also represented by your own counsel.

However, in many cases, many family members proceed without an attorney and avail themselves of resources through state agencies, the courts, and nonprofit organizations, such as the Massachusetts Guardianship Association, to secure the information they need to be successful. Most Probate and Family Courts also have an information session where volunteer attorneys can answer questions and help fill out forms.

HEALTH CARE AGENT/PROXY AND ALTERNATE

If a person with a special need or disability has capacity, he or she can appoint a health care agent to make health care decisions on behalf of the individual, including life-sustaining treatment. This is done by preparing a health care proxy, which is a document that authorizes a health care agent to make health care decisions on behalf of the special needs individual, if the individual is unable to do so.

It is imperative that an individual with capacity sign a health care proxy at age 18 for two reasons. First, while the disabled individual may be competent to make health care decisions, it will allow the agent to participate in the decision-making process so that the most informed decision can be made. Second, if the individual later becomes unable to make medical decisions due to incompetency, the agent will be able to make medical decisions on behalf the individual. It is recommended that families' start discussing the appointment of a health care agent when the child while the child is 17 and seek out an attorney before the child turns 18 so that when the child turns 18, the documents can be quickly put into legal effect.

MEDICAL RELEASE

An individual with capacity can also sign a medical release form or other private insurance forms to authorize another to receive medical information on their behalf.

HIPAA AUTHORIZATION FORM

The Health Insurance Portability and Accountability Act of 1996, known as HIPAA, is the primary federal regulation that protects an individual's health care records. When a special needs individual reaches the age of 18, a parent or guardian no longer has the authority to review the child's medical records. Therefore, the special needs individual with capacity will need to execute a HIPAA Authorization Form to give his or her agent the ability to review his or her medical records so that the agent can access medical records and consult with health care providers on behalf of, or in the company of, the individual with special needs.



FINANCIAL ADVOCACY

This chapter explains several options that can be used alone, or in combination, to help a disabled individual manage money. The options presented in this chapter differ from one another in terms of control retained by, or withheld from, the disabled individual.

JOINT BANK ACCOUNT

When a special needs person reaches the age of 18, he or she is presumed able to manage finances. If the person is working or is receiving government benefits, setting up a joint bank account titling the account in the person's name and in another's name will allow an advocate to assist in managing the bank account and the disabled person's financial affairs. Before doing so, you should seek out an attorney who handles special needs to see if this is the best avenue for managing assets because there can be drawbacks for such a strategy. For instance, if the joint account holder predeceases the disabled person leaving the him or her as the sole owner of the account, active steps will have to be taken to have someone placed on the account as a joint account owner, or a durable power of attorney will have to be prepared so that an agent can manage the account.

REPRESENTATIVE PAYEE

If the special needs person qualifies for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), the Social Security Administration (SSA) will provide income to the disabled individual. SSA operates under the presumption that the individual is competent and can manage his or her financial affairs. If the disabled individual is unable to manage his or her affairs, an individual can be appointed to be the Representative Payee who will receive the government benefit on behalf of the disabled individual. The SSA generally requires a letter from the disabled individual's physician that a Representative Payee should be appointed to receive the government benefit.

POWER OF ATTORNEY

A Durable Power of Attorney is a document that allows an individual (the “principal”) to appoint an agent to make financial decisions on behalf of the principal. If a special needs individual has the capacity to sign legal documents, he or she should sign Durable Power of Attorney so that an agent can be appointed to manage his or her financial affairs. If the disabled individual is later unable to manage his or her financial affairs, the agent can then make the financial decisions for the disabled individual. The document can be specifically crafted to each individual’s situation providing either broad or limited authority. Another reason for having a Durable Power of Attorney put in place is that it can avoid the need for a conservatorship, since the agent can manage the financial affairs for the disabled individual.

ABLE ACCOUNT

An Achieving a Better Life Experience (ABLE) Account is an account that an eligible individual can use to save funds for his or her disability-related expenses. To be eligible, the individual must be blind or disabled by a condition that began before the individual’s 26th birthday.

A person is considered eligible for an ABLE account if he or she:

- is entitled to benefits based on blindness or disability under Title II (SSDI) or Title XVI (SSI) of the SSA, or
- certifies that he or she is blind, disabled, or has a condition listed on the List of Compassionate Allowances maintained by the SSA. Except for those individuals who have a compassionate allowance condition, he or she has received a written diagnosis of his or her impairment from a licensed physician.

There are limits to the contributions to and balances of this type of an account. Further, funds in an ABLE account may only pay for qualified disability expenses, which is any expense related to the designated beneficiary as a result of living with disabilities. These may include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expense, financial management and administrative and other expenses, which help improve the health, independence, and/or quality of life.

The account owner is the eligible individual and is also referred to as the designated beneficiary. If the account owner is a minor or is unable or chooses not to manage the account, a person with signature authority (PSA) must be designated on the account. A PSA must be a parent, legal guardian, or have Power of Attorney for the account owner. The PSA must neither have nor acquire any beneficial interest in the account and must administer the account for the benefit of the account owner.

Fidelity is responsible for managing ABLE accounts in Massachusetts. To find out more or open an account, please contact Fidelity or visit Fidelity’s website at <https://www.fidelity.com/able/attainable/overview>.

FIRST-PARTY SPECIAL NEEDS TRUST (SNT)

A person with a disability, who also has capacity, can create a trust and transfer their assets to a trustee to assist with the management of funds. A special needs trust funded with the disabled individual’s money is called a first-party SNT, sometimes known as a “Medicaid Payback Trust”. First-Party SNTs can also be created by others to help protect individuals with disabilities who receive public benefits and would benefit from having funds in a trust used to maintain their quality of

life. When a person who receives public benefits also receives money in his or her own name, rather than in trust, the public benefits may be jeopardized. This could arise when the individual receives a personal injury or divorce settlement, or an inheritance or gift. There are several planning options. You should seek out an attorney who practices in the area of special needs law to see if a first-party SNT is the best avenue for managing assets because there can be drawbacks to such a strategy. The advice of an experienced special needs planning attorney is critical to designing and executing a good plan.

THIRD-PARTY SPECIAL NEEDS TRUSTS (SNTS)

Most parents want to leave assets to their children when they die; however, if a person with a disability receives assets outright, the results can be disastrous. The person will lose Medicaid and SSI, and the assets may also be subject to recoupment by Medicaid, or by the State if the person is receiving residential services.

Learning this, some parents are inclined to disinherit the child with a disability, leaving everything to the non-disabled children with verbal instructions to use part of the inheritance for the benefit of the sibling with a disability. This is what is sometimes referred to as a 'gift of moral obligation,' and it can be equally disastrous. For example, the non-disabled child may not use the inheritance on their sibling's behalf, and is under no legal obligation to do so. The spouse of the non-disabled child may want to use the assets for other purposes not related to the sibling with a disability. Even if the non-disabled sibling uses the assets exactly as the parents intended, they can be claimed by the non-disabled sibling's creditors, can have negative tax consequences on the non-disabled sibling, and can be claimed by a spouse in the event of divorce.

Instead, it is recommended that parents establish a third-party special needs trust (SNT). Unlike a first-party SNT, a third-party SNT is funded only with money and assets of other people, not with assets held in the disabled person's name. A SNT can protect the assets while, at the same time, making the assets available to protect and enrich the life of the person with a disability without jeopardizing benefits available from the government. A SNT is a unique legal document that contains a set of instructions describing how assets placed into trust will be administered on behalf of a person with a disability. It must be carefully worded and is best written by a professional who is familiar with disability services and programs in your state.

Parents and other family members can use a SNT to hold assets for a disabled person. Even families with modest assets should establish a SNT; typically, such trusts are not funded until one or both parents die. A SNT can be funded through life insurance or estate assets distributed through one's will.

SNT funds can be used to purchase independent professional opinions as necessary, pay for services not otherwise available through public benefits programs, provide additional recreation and other amenities, pay for a private residential placement, or a vehicle used to transport the beneficiary of the trust.

At the death of the beneficiary, any remaining trust property can be distributed to other family members or even to a charity.

CONSERVATORSHIP

If an individual with special needs does not have the capacity to sign a Durable Power of Attorney, then as a last resort, a conservatorship may be required. However, most attorneys advise not to do this but to utilize the other options discussed above, because of the cost and court oversight involved with a conservatorship.

A conservator is an individual who is granted legal authority to manage the financial affairs of a person deemed unable to manage their financial affairs. Similar to guardianships, discussed earlier in this Toolkit, the Probate and Family Court appoints the conservator. As it is a formal legal appointment and the court retains oversight over the estate of the incompetent individual, meticulous record keeping is necessary as annual accountings must be filed with the court. If your disabled child is nearing the age of 18, you should seek legal counsel from an attorney who handles guardianship and conservatorships to guide you through the legal process.

Medical Insurance



There are several types of insurance coverage for health care services:

Private Health Insurance (including group health plans);
Public Health Assistance (Medicaid and Medicare); and
Self-funded / Self-Insured health benefits plans.

PRIVATE HEALTH INSURANCE

Many people receive medical insurance through their work, and some purchase and pay for coverage themselves. In addition to covering routine care, medical insurance can be used to pay for many disability-related services and treatments, including autism-related services and mental health care.

Coverage for autism treatments. Under the ARICA law (An Act Relative to Insurance Coverage for Autism), insurance companies in Massachusetts must provide coverage for the diagnosis and treatment of autism spectrum disorder, which affects 1 out of every 68 residents of Massachusetts. The covered services include evaluations and therapies like Applied Behavior Analysis (ABA), floor time, occupational therapy, and speech and language therapy. Treatments with a psychiatrist, psychologist, or social worker are also covered, as are social skills groups. There is no lifetime cap on benefits or age limit to receive the services.

Most insurers are required to comply with ARICA as a condition of doing business in Massachusetts, as are Group Insurance Commission (GIC) plans that cover state employees. Self-insured group health plans are not required to comply with the law (an employer is self-insured when, instead of paying an insurance company to cover its employees' health care costs, the employer covers the cost itself).

The Autism Insurance Resource Center can tell you if your company has to comply with the law, and the staff may be willing to advocate for coverage with your company (774-455-4056, www.disabilityinfo.org/airc).

Coverage for mental health services. Under the Mental Health Parity Law, medical insurers in Massachusetts are supposed to pay for treatment of mental health conditions to the same extent that they would cover a physical illness. For adults (those who are 19 and older), the disorders that must be covered include schizophrenia, schizoaffective disorder, major depressive disorder, bipolar disorder, and obsessive-compulsive disorder. The coverage is broader for children (those under 19). In addition to the disorders that apply to adults, health plans must provide coverage of mental, behavioral, or emotional disorders that substantially interfere with or substantially limit the covered person's social interactions and ability to function. The insurance company does not have to pay for services that are provided in a school setting or for services that are provided by the Department of Mental Health.

Coverage to age 26. By law, the children of a subscriber can remain on their parent's policy until they are 26. A subscriber's disabled child who is 26 or older may be able to retain coverage if the policy or the employer allows it, so you should check to find out.

PUBLIC ASSISTANCE PROGRAMS

Public Assistance Programs include Medicaid/MassHealth (Individual State Plans, EPSDT Program, Managed Care, or Waiver Programs) and Medicare coverage.

Medicaid is a federal-state entitlement program for low-income Americans. There are three basic groups of low-income people: parents and children, elderly, and the disabled. The eligibility rules for our state Medicaid program, known as MassHealth, vary depending on the program. Think of MassHealth as a room with many doors. Not everyone enters the program through the same door, but for the most part, once you get inside (i.e. become eligible) the available benefits are the same and are dependent on the necessity of the member. One key difference to this notion is for people who need long term care benefits. Long term care benefits consist of:

1. Institutional or nursing home level care;
2. Some community based services; and
3. Home and Community based Waiver Services which either prevent institutionalization or return members to the community from an institutional setting.

To be eligible for Medicaid, there are income limits depending on the program. Those income calculations are complex depending on the program. For those MassHealth programs that require limited financial resources, generally you must have no more than \$2,000 in countable assets.

Each State's Medicaid State Plan provides the following Mandatory Services:

- in- & out-patient hospital treatment;
- lab test & x-rays;
- EPSDT services;
- home healthcare;
- physician services;
- nurse midwife;
- family assistance; and
- nursing homes for those over the age of 21.

In addition, each State may elect to include any of the following Optional Services:

Residential Treatment Centers • Optical appliances • Dental • Optometry • Chiropractic • Psychology • Podiatrist • Prosthetics & Orthotics • Drugs during long-term care • Durable Medical Equipment • Hearing Aides • Hospice • Transportation • Private Duty Nursing services • Personal Care services • Clinic services • Therapies (ST, OT & PT) Intermediate care (ICF/MR) and • In-patient psychiatric care for under 21 & older than 65

Among the mandatory Medicaid services contained in the State Medicaid plan is the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. EPSDT services must be made available to every Medicaid-eligible child under the age of 21. Under EPSDT, the state must provide four types of screening services: medical, vision, dental, and hearing. Also, it is required to provide coverage for medically necessary treatment.

EPSDT covers a wide range of treatment services, including all Medicaid mandatory and optional services when they are medically necessary to “correct or ameliorate defects and physical and mental illnesses and conditions” regardless of whether such services are covered under the state plan. Covered services under the EPSDT Program may include: case management, home health care, personal care, private duty nursing, physical therapy and related services, respiratory care, hospice care, rehabilitation, durable medical equipment, hearing aids, eyeglasses, medically necessary orthodontic care, and personal care services.

In order to obtain and maintain coverage, your treating physician must provide written documentation that the requested service is medically necessary. The agency or individual that provides services should always keep precise notes on your condition and continued need for the particular service. Without this documentation, medically necessary services are frequently reduced or terminated.

Medicaid-funded Home and Community-Based Waiver Programs - many States offer Medicaid-funded Waiver Programs that provide individuals with disabilities care in the home and community as an alternative to institutional care.

In Massachusetts, we have a brain injury waiver, a money follows the person waiver to return to the community from institutional care, a Katie Beckett (Kaleigh Mulligan) waiver for nursing services for medically fragile children, a waiver for intellectually disabled adults, and a children’s autism waiver.

The financial and other eligibility requirements are complex and vary for each waiver program. Fortunately, each waiver program has a partner state agency to assist members in applying for and maintaining access to this critical coverage.

Medicare is a partner program to Social Security, which provides a health and financial safety net to those 65 years and older and to those declared disabled for 24 months. Medicare is divided into two parts. Part A covers hospital and limited nursing care. Part B, which requires an extra premium, covers physician services, as well as a variety of therapies and other items. Medicare also has co-payments and deductibles.

SELF-FUNDED / SELF-INSURED PLANS

Self-funded or Self-Insured Plans are insurance plans offered by a private employer, in which the employer (not an insurance company) assumes the risk of insuring its employees. Under such an arrangement, the employer hires an insurance company to administer the plan and handle all of the claims. Self-funded plans have greater latitude as to what they do and do not cover under the plan.

*Note: Under most private insurance policies, there is a provision for continued dependent coverage for disabled dependent adults. Check your individual policy language to see what is required in order to extend your private dependent coverage of your disabled child. Typically, proof of disability is required.

MASSACHUSETTS AGENCIES THAT PROVIDE SERVICES



DEPARTMENT OF DEVELOPMENTAL SERVICES

The Department of Developmental Services is an agency within the Executive Office of Health and Human Services whose mission is to create, in partnership with others, opportunities for individuals with intellectual disabilities to participate fully and meaningfully in, and contribute to, their communities as valued members. DDS provides specialized services and supports to adults with intellectual disabilities and children with developmental disabilities. The types of specialized services and supports include day supports, employment supports, residential supports, family supports, respite, and transportation. Services are provided through facilities and community-based state operated programs and by contracting with numerous private provider agencies.

ELIGIBILITY

An individual is eligible for services if he or she has significantly sub-average intellectual functioning existing concurrently with and related to significant limitations in adaptive functioning, which intellectual disability originates prior to age 18.

Intellectual Disability: an individual who 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.

Developmental Disability: 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.

The individual or his or her advocate must submit a comprehensive diagnostic report from a licensed qualified practitioner such as a Ph.D., Psy.D., M.D. etc. This document must verify the diagnosis and would include IQ and cognitive testing.

Application Process: The application process is initiated by a parent when the applicant is under the age of 18, a Guardian, or the adult disabled person if he or she has the capacity, by sending an application form to the DDS Regional Eligibility Team. The DDS application is available online on the DDS website:

<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/support/developmental-services-eligibility-application.html#form>

An important component of the application process is legal authorization to proceed with the process. Applicants who have capacity, or their Guardians, must give written permission so that DDS can proceed with the eligibility process. This does not mean that an applicant cannot get help from a family member, friend or agency. However, if the applicant chooses to have someone assist him/her, he or she will also need to authorize that by signing a permission form. This permission is required if the applicant wants DDS to be able to communicate directly with this person on their behalf. These authorizations are now a vital part of the application form.

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.

Generally, a written decision will be sent to applicants 60 days after the Regional Eligibility Team receives all of the necessary documentation and has had the opportunity to conduct an intake interview. There are three types of eligibility determinations: eligible, ineligible and deferral of eligibility determination. If applicants are found eligible, applicants will be given the name of the area office that will be responsible for service planning and prioritization. If applicants are found ineligible, they will be given information about their appeal rights. If DDS is unable to render a decision, applicants will be told what additional information is still needed to complete the eligibility process.

MASSCAP

DDS uses the MASSCAP (Massachusetts Comprehensive Assessment Profile) to assess what services an individual needs and how urgently those services are needed. MASSCAP assists DDS to evaluate individual needs and capabilities along with the strengths and needs of the individual's caregivers. The MASSCAP consists of the following three parts.

The ICAP (Inventory of Client and Agency Planning) is a tool that assesses the individual's adaptive functioning and the level of support and supervision that the person needs. The areas assessed by ICAP are Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. The ICAP scores range from zero to three points. Zero points meaning never or rarely does well in that area, and three points meaning does very well in that area. This information is then entered into the ICAP application to determine the total ICAP score.

The CCA (Consumer and Caregiver Assessment) is a tool that assesses the resources and supports that are currently in place for the individual and provides information to assist in evaluating the capacities of the caregivers. The 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.

Finally, the information provided by the ICAP and the CCA, as well as the direct observation of the individual and interviews with family members, is reviewed by individuals with training and experience in the field of intellectual disabilities that make a decision based upon professional judgment.

The MASSCAP process will typically provide the information necessary for the Department to determine whether an individual has an assessed need for a requested service. In certain circumstances, the Department may request supplemental functional or targeted assessments in order to provide additional information in making the determination of an individual's need for supports.

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. Under Priority 1 needs, the service planning should be initiated and services should be arranged or provided within 90 days.

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 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.

SUPPORTS INTENSITY SCALE

The Supports Intensity Scale ("SIS"), which has been developed by the American Association on Intellectual and Developmental Disabilities ("AAIDD"), is utilized by the Department 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 valid assessment requires the participation of at least two respondents who have known the individual for at least three months, preferably the individual and two people who are knowledgeable about the individual's daily life skills. It is optimal that respondents are from diverse areas of the individual's life, such as one family member and one professional, or one residential professional and another from the Work/Day setting.

Topics assessed are common to anyone's quality of life, including medical and behavioral supports, home and community living, social activities, lifelong learning, employment, health, safety, protection and advocacy. The SIS Assessor will identify the types of supports required for an individual to be successful; how frequently an individual will need these supports; and how much time the supports will be needed daily.

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 legal counsel be retained for the proceedings.

DEPARTMENT OF MENTAL HEALTH

The Department of Mental Health is an agency within the Executive Office of Health and Human Services whose mission assures and provides access to services and supports to meet the mental health needs of individuals of all ages, enabling them to live, work and participate in their communities. The Department establishes standards to ensure effective and competent care to promote recovery. The Department sets policy, promotes self-determination, protects human rights and supports mental health training and research. This mission is accomplished by working in partnership with other state agencies, individuals, families, providers and communities. Mental health is an essential part of health care services. DMH promotes mental health through early intervention, treatment, education, policy and regulation so that all residents of the Commonwealth may live full and productive lives.

DMH RESOURCE GUIDES

The Department of Mental Health publishes several resources guides that help consumers, families and the general public find information about their agency, their services and other statewide services and programs in the mental health community.

- a.) The DMH Resource Guide is a directory of the DMH, its Areas, Service Site Offices, facilities and contact information. A handy listing of cities and towns will direct you to the appropriate DMH Site Office and contact.
- b.) The DMH Consumer and Family Resource Guide is a listing of information and referral resources made available from the DMH Information and Referral Line, toll free at 1-800-221-0053. Tailored for the needs of consumers and families, this guide provides information and referral in a variety of categories from accessing DMH services to listings of consumer organizations to contact information for legal resources for consumers.
- c.) The Emergency Services Programs (ESP) Resource Guide lists all ESPs statewide, their location, corresponding cities and town and toll-free crisis number.
- d.) The DMH Young Adult Resource Guide has been developed and updated to reflect the changing needs of the young adult population in DMH as well as those services and supports that accompany the young adult's journey through education, employment, transportation, and housing. This guide is intended for young adults who need assistance in navigating these areas so that they may achieve their goals of recovery and become successful, independent adults who live and thrive in the community.
- e.) DMH Multicultural Populations Resource Guide contains information about agencies and institutions in the Commonwealth that offer culturally and linguistically appropriate services.

ELIGIBILITY

Children and Adolescents

A child or adolescent must be younger than 19 at the time of application and have a serious emotional disturbance that 1.) has lasted or is expected to last at least one year and 2.) has resulted in functional impairment that substantially interferes with or limits the child's or adolescent's role or functioning in family, school or community activities; and 3.) meets the clinical criteria, but is not solely within one or more of the following categories: a.) developmental disorders usually

first diagnosed in infancy, childhood or adolescence, such as mental retardation or pervasive developmental disorders; or b.) cognitive disorders, including delirium, dementia or amnesia; or c.) mental disorders due to a general medical condition not elsewhere classified; or d.) substance-related disorders.

AGE 19 AND OLDER

An adult age 19 and older must have a serious and long-term mental illness that lasted or is expected to last, at least one year; and that substantially interferes with one or more major life activities such as eating, bathing, dressing, maintaining a household, managing money, taking prescription medication, or accessing generic community services.

The mental illness must also interfere with their functioning in social family or vocation / education contexts. The adult must also meet the clinical criteria for one of the following disorders: Schizophrenia, and other Psychotic Disorders; Mood Disorders (excluding Dysthymia and mood disorders due to a general medical condition); Anxiety disorders; dissociative disorders; borderline personality disorder; attention-deficit/hyperactivity disorder (which includes conduct disorder, oppositional-defiant disorder, and disruptive behavior disorder not otherwise specified.

APPLICATION PROCESS

There are two different types of applications, depending on the age of the applicant as discussed above. The forms are available at the website: <https://www.mass.gov/dmh-application-forms>. The applications are filed with the DMH area office that covers the town the applicant lives in. A list of the towns is available at the DMH website. The application is called a “Request for Services Form.” Within seven (7) days of receipt of a Request for Adult Services application, DMH will contact the applicant or guardian by telephone. The purpose of the phone contact will be to: acknowledge DMH’s receipt of the Request for Adult Services application, review the determination process, confirm the applicant or guardian wants to continue the determination process, assess the applicant’s immediate or emerging needs and respond appropriately, and initiate the collection of relevant medical and other information supports the applicant’s request for services.

A DMH Clinical Service Authorization Specialist may require, as necessary, a face to face meeting with the applicant and/or guardian to further discuss and assess the needs of the applicant. In most instances, a face to face meeting will occur at a DMH office. In other instances, a face to face meeting may occur at another agreed upon location.

The DMH Area Director or designee will make decisions regarding service requests upon receiving and reviewing information in accordance with the DMH regulations. <http://www.mass.gov/eohhs/docs/dmh/regs/reg-104cmr29.pdf>.

AUTHORIZATION FOR RELEASE OF INFORMATION

An Authorization for the Release of Information (2-way) is included with the Request for Services Application. Applicants will need to submit a separate Authorization for Release of Information for each person, agency or facility the applicant authorizes DMH to receive and give information. Applicants are encouraged to submit 2-way releases to efficiently facilitate communication.

If the applicant is found to meet the clinical criteria for services, the next step is a “needs and means interview/meeting.” The Area Director or designee must determine whether the individual needs DMH Services. Since the availability of DMH services is limited, DMH must prioritize to

whom and how those services are provided. DMH regulations establish the criteria to be used to determine who is authorized to receive services and how those services are assigned.

APPEALS

If an applicant is not approved for DMH services based on a clinical criteria, that determination may be appealed by the applicant, the applicant's legally authorized representative, if any, or a person designated by the applicant when there is no legally authorized representative. DMH staff will provide the applicant with the necessary names, addresses and telephone numbers to initiate the appeal.

The applicant wishing to appeal should request an informal meeting with the Area Director or designee, within ten (10) days of receiving the notification of denial to ask questions and resolve any issues or ask that this informal meeting be waived (the applicant may bring other persons to this meeting if desired). If the informal meeting has been waived or if the applicant is still dissatisfied with the decision, the applicant may file a written notice with the area medical director, a Request for Reconsideration by the Area Medical Director within ten (10) days after the conclusion of the informal conference or the agreement to waive. The Area Medical Director must render a decision on the Request for Reconsideration within twenty (20) days of receipt of the request, unless the time is extended by mutual consent of the Area Medical Director and the person filing the Request for Consideration.

If the denial is not reversed by the Area Medical Director, the applicant may appeal the decision by petitioning the DMH Commissioner or designee for a fair hearing pursuant to 104 CMR 29.16(5). This petition for fair hearing must be submitted to the Commissioner within 20 days after receiving the denial. The hearing officer must render a decision within 20 days of the close of the hearing. Within 15 days after receipt of the hearing officer's recommended decisions, the Commissioner must issue a decision.

You may contact the DMH Information and Referral Line at 1-800-221-0053 (Monday through Friday, 9am – 5pm) if you have questions about the application process or need information about where an application should be sent. The DMH website also contains a great deal of information: <https://www.mass.gov/orgs/massachusetts-department-of-mental-health>.

Under the Informal Rules of the Administrative Procedures Act, it is strongly encouraged that legal counsel be retained for the proceedings.

MASSACHUSETTS REHABILITATION COMMISSION

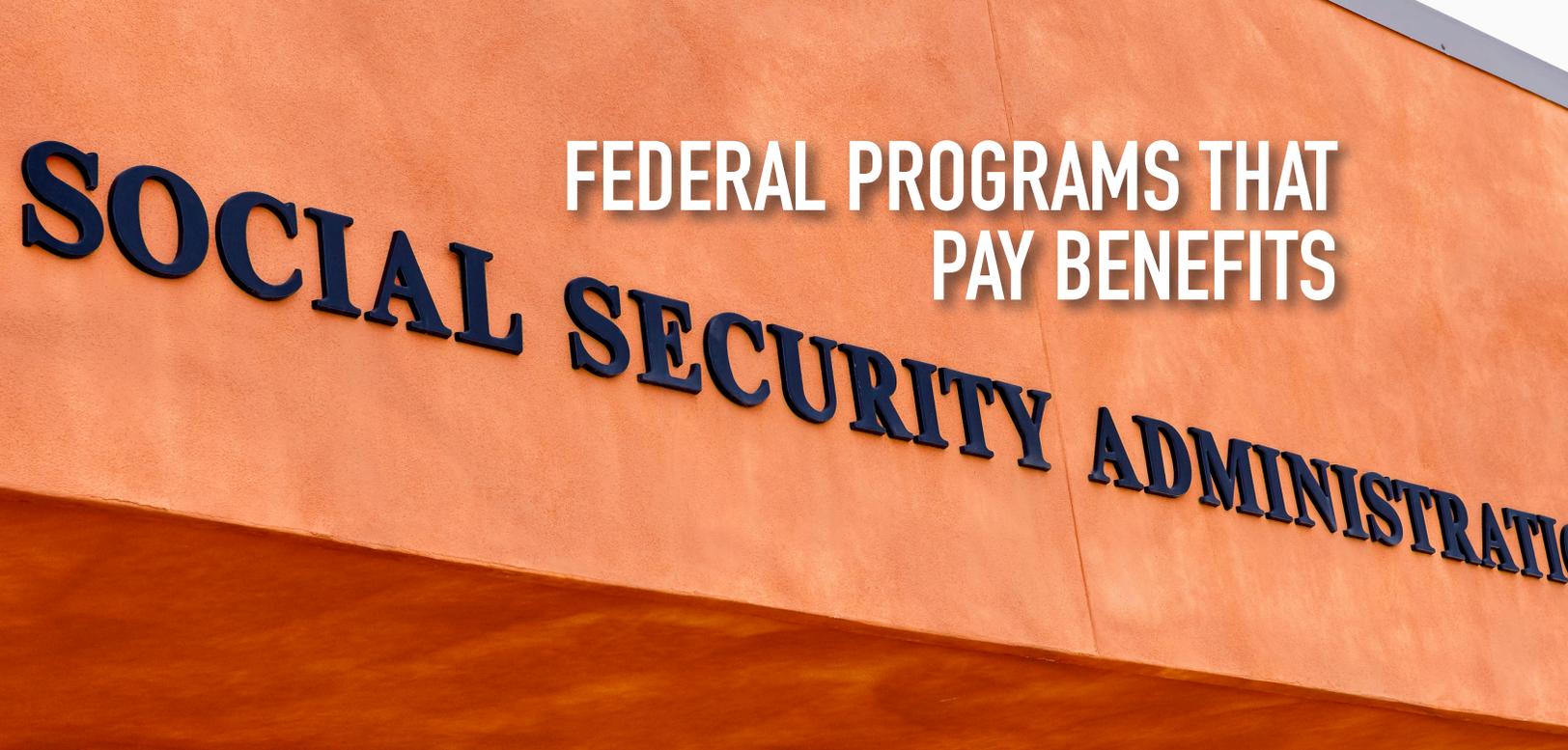
The Massachusetts Rehabilitation Commission (MRC) provides vocational and related services to people with disabilities. MRC services are generally provided to adults, although students can begin transition services while they are still in school, usually about two years before they are due to graduate. MRC does not serve individuals who are blind (they must obtain services through the Massachusetts Commission for the Blind). MRC's vocational service currently includes the following: evaluations, interest and aptitude testing, college or vocation training, job placement assistance, counseling and guidance, supported employment, skills training, job coaching and tutoring. MRC also offers tuition assistance and limited housing.

To qualify for services, a person must have a serious physical or mental impairment that substantially interferes with their ability to work and they must need vocational services in order to prepare for, engage or retain employment. Someone who receives SSI or SSDI is presumed to be eligible. Alternatively, MRC will arrange for an assessment of a person's disability through the Disability Determinations Unit at the University of Massachusetts in Worcester.

A student's school department can refer him or her to MRC, or a person can contact MRC directly by calling the MRC main number (800-245-6543) or any local office. An interview will be scheduled. MRC has 60 days from the date of application to determine if an applicant is eligible for services.

More information can be found at the website: <https://www.mass.gov/orgs/massachusetts-rehabilitation-commission-0>.

A Family Guide to Transition Services is also available from the Federation for Children with Special Needs - <https://fcsn.org>.

The image shows the exterior of a Social Security Administration building. The words "SOCIAL SECURITY ADMINISTRATION" are mounted on the wall in large, dark blue, three-dimensional letters. The wall is a light orange or terracotta color. The text "FEDERAL PROGRAMS THAT PAY BENEFITS" is overlaid in white, bold, sans-serif font in the upper right portion of the image.

FEDERAL PROGRAMS THAT PAY BENEFITS

SOCIAL SECURITY ADMINISTRATION

SOCIAL SECURITY ADMINISTRATION

SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a federal “safety net” program that pays a subsistence amount of income every month. The income numbers in this section on SSI are for the year 2018; most numbers are adjusted annually for inflation. In order to qualify, someone who is 18 years of age or older must:

- Be disabled according to Social Security’s standards;
- Have low income, which in general is no more than \$1,170/month that is from work (\$1,950/month for a blind person), or no more than \$770 which is not from work, or some combination of the two; and
- Not own more than \$2,000 in assets in his or her own name.

Children (under age 18) can receive SSI, but it can be difficult for them to qualify because their parents’ income and assets are counted (for example, a family of three cannot have more than about \$4,000 in the bank). However, when someone turns 18, the SSI program only considers his or her own income and assets, which is the reason most people wait until age 18 to apply for benefits.

SSI Benefit Amounts/Medicaid Entitlement

The maximum amount that the SSI program will pay is currently about \$735/month. Recipients who live in Massachusetts receive a small supplement, they will get two checks every month; one from the federal government and one from the state. Massachusetts residents who receive SSI automatically receive Community MassHealth (Medicaid) free of charge.

Resource Limits

The SSI program has a \$2,000 resource limit that is strictly enforced. The resources that Social Security counts toward the \$2,000 limit include:

- checking and savings accounts;
- savings bonds (including accrued interest);
- stocks, bonds, and mutual funds;
- UTMA (Uniform Transfers to Minors Act) account for someone who is 21 years of age or older. An UTMA account is a custodial bank account for a person who is under age 21).

Some of the resources that the program does not count toward the \$2,000 limit include:

- personal property such as furniture, household goods, appliances, computer, TV, etc., regardless of the items' aggregate value;
- residence (house, condominium, or shares in a housing cooperative);
- automobile of any value, including an adapted vehicle;
- medical equipment such as a wheelchair;
- UTMA account for someone who is under age 21;
- 529 education plan;
- funds in a special needs trust that is properly written and is being managed correctly according to the SSI rules; and
- an ABLE savings account

Limited Ability to Work

In order for an adult to get benefits, he or she must persuade Social Security that he or she is medically disabled within the program rules. Social Security considers some disabilities to be so severe that the person will be approved for benefits more or less automatically (these are called “listed impairments”). The listed impairments include conditions like Intellectual Disability, schizophrenia, psychosis, non-Mosaic Down Syndrome, lack of vision or speech, and inability to walk.

If the person does not have one of the listed impairments, Social Security must determine that the person’s disability prevents him or her from working competitively and earning more than about \$1,170/month. Social Security calls the ability to work and earn this level of income “substantial gainful employment.”

Income Limits

Earned Income. If someone who receives SSI has any earnings from work, his or her monthly benefit will be reduced and could be eliminated if his or her earnings are too high. Social Security disregards the first \$85 of earned income and 1/2 of earnings over \$85. However, Social Security is not supposed to consider a person’s earnings while he or she is under the age of 22 and attending school as long as the earnings do not exceed about \$1,790/month.

Unearned Income. If someone has income that is not from work, his or her SSI check will be reduced by one dollar for every dollar of unearned income that is received. Such “unearned income,” includes items such as Social Security Disability payments, a pension, an annuity, and child support.

In-kind Income. A person’s SSI benefits will be reduced if he or she receives any “in-kind” income, which is food and shelter the person receives and does not pay the full value to acquire. For example, if an adult recipient lives with his or her parents and does not pay for the full cost of his or her room and board, his or her monthly benefit will be reduced by 1/3 (about \$246/month). Fortunately, the person will not lose more than \$246/month of benefits no matter how much “free” room and board he or she receives.

Child Support Payments

If a person's non-custodial parent makes child support payments on the person's behalf, the payments will be considered to be the person's income and, depending on the amount, may prevent the person from getting SSI. To avoid this result, the child support payments can be assigned to a special needs "payback" trust. In order for SSI to approve this arrangement, a judge must order the payments to be deposited into the trust, and the custodial parent has to irrevocably give up the right to receive the payments. This can be done when the initial child support order is being put into place or later through a proceeding that modifies the original order.

Appealing a Denial of Benefits

Someone who is denied SSI benefits can appeal through several stages of review, beginning with an impartial reconsideration at the local field office. If a person is denied at that level, he or she can request a hearing with an Administrative Law Judge. There are higher levels of review but most applicants do not use them because of the difficulty involved. The denial of benefits notice will describe the person's appeal rights and will include resources for finding legal help.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Almost everyone is familiar with the Social Security program that pays benefits to people who have worked and then retire. Social Security has another program that pays benefits to disabled workers and to workers who have dependent children—this program is called Social Security Disability Insurance (SSDI).

The first step to collecting Social Security benefits is to establish a work record. In general, a person must have worked for a minimum of 40 quarters (10 years total), although younger workers can work fewer quarters. The quarters do not have to be consecutive as long as they are in "covered" employment, which means that Social Security payroll taxes (FICA) were deducted from the earnings.

After a person has established his or her work record, the person can collect a monthly cash benefit when he or she reaches normal retirement age (this will depend on the year the person born). The person may also be able to collect benefits if he or she becomes disabled and has to stop working before he or she reaches retirement age.

Anyone who participates in Social Security can qualify for Medicare insurance, although some participants may have to wait 24 months to receive benefits.

Benefits for Minor Children and Adult Disabled Children

An important feature of the SSDI program is that it will pay benefits to a worker's dependent children who are under age 18 (19 if they are still in school). There are three ways that these children can collect their parent's work record:

- The parent reaches retirement age and begins to draw benefits;
- The parent becomes disabled before reaching retirement age and collects benefits; or
- The parent dies.

If a child of a worker is over 18 and has a disability, the child may be able to collect benefits for the rest of the child's life as a "disabled adult child." In order to qualify, the child's disability:

- Must have been present before the child was age 22;
- Must prevent the child from earning a substantial amount of money (in general, this amounts to \$1,170/month in competitive employment, or less if the child pays for work-related expenses or gets extra help on the job, such as assistance from a job coach);
- Must have been continuous from before the child was age 22 through the time the child is claiming benefits (if the earnings are substantial for more than 9 months, the "continuous" aspect of the child's disability may be broken); and
- The child must be unmarried, or if married, his or her spouse must be receiving SSI or SSDI

A Person with a Disability Can Collect on His or Her Own Work Record

It is not unusual for someone with a disability to get a job but then lose it or have to stop working because his or her disabling condition worsens. If this happens, the person may be able to collect SSDI benefits based on his or her own work record if he or she has accumulated enough quarters for a person that age.

SSDI Benefit Amounts

The benefit amount for a Social Security retiree or someone who has become disabled and unable to work before he or she reaches retirement age will be based on the amount the person has paid into the Social Security system. A disabled adult child's benefit will be based on the parent's check. In general, a disabled adult child can receive 50% of the parent's benefit while the parent is living, and 75% of the amount the parent was receiving at the time of the parent's death. These percentages may be lower if there are other family members who are collecting on the worker's record such other children, spouses, ex-spouses, and parents.

No Limits on Assets or Unearned Income

The SSDI program does not consider the amount of resources a person owns, and it disregards income that is not from work (such as interest, dividends, capital gains, income from an annuity, alimony, and child support payments). Only a person's earnings from employment or self-employment are considered (in general, such earnings may be not more than \$1,170/month).

Getting SSI and SSDI at the Same Time

Some people get SSI and SSDI at the same time. If a person's SSDI benefit is below the maximum level for the SSI program (about \$750/month), he or she can apply for SSI payments to supplement his or her SSDI benefit. The person would have to meet the income and asset restrictions for the SSI program (limits on earned and unearned income and no more than \$2,000 in resources).

SOCIAL SECURITY

Social Security benefits are available to disabled dependents of a parent who collects Social Security benefits or who dies. Individuals who receive Social Security also receive Medicare. Social Security benefits count as income for SSI purposes and, in some cases, can reduce or eliminate SSI benefits.

HOUSING



WHERE ADULTS WITH DISABILITIES LIVE AND WHO PAYS FOR IT

There are no entitlements to residential services for those over the age of 22.

There are numerous kinds of residential arrangements and more are cropping up every year as parents and other family members, as well as providers, become more creative in trying to meet the ever-growing need for stable and supported housing for adults with disabilities. Presently, most adults with disabilities remain at home with parents or other family members for the better part of their adult lives.

It is very important to have a plan for ongoing supported housing long before it is needed as resources are scarce and the waitlist is very long for many traditional housing options.

Kinds of residential arrangements

- Traditional group home (4 -5 people)
- Non-traditional group residence (8-12 people)
- With a host family (Shared Living)
- With a roommate (with or without a disability)
- Alone with supports, such as staff assistance with medication, medical appointments, food shopping, food preparation, hygiene, housecleaning, transportation, rent subsidy to reduce cost

The cost of residential services

Guiding principle: The more people who live together, the lower the cost.

The calculations of a residential annual budget are driven by these costs:

- \$\$\$\$\$ staff assistance, medical, therapeutic services
- \$\$\$\$ down payment for a house, mortgage, taxes, rent
- \$\$\$ food and house supplies
- \$\$ utilities
- \$\$ residents' personal expenses (cell phone, 1:1 staff, recreation, toiletries, etc.)
- \$\$ transportation
- \$ management (payroll processing, staff hiring/covering staff absences, landscaping, snow removal, emergencies like no heat, etc.)

All residential plans are very individualized to the client, but these costs can run from a simple \$12,000/year to \$200,000/year or more for individuals with more complex needs.

The funding sources for residential services

State agencies like DDS and DMH are the major providers of residential services (MRC also has a limited amount of funds). Money flows through these state agencies to “residential providers” that are non-profit agencies such as TILL, Vinfen, Advocates, and the Arcs.

- DDS requirements to receive residential services:
 - Must have a diagnosis of Intellectual Disability (ID)
 - Those with autism cannot receive residential services at this time
 - Must be Priority One due to health and safety issues such as sick, single, aging parent, etc.
- DMH or MRC residential services are not meant to be lifetime services, but for shorter timeframes with a goal of returning clients to the community and community based supports.

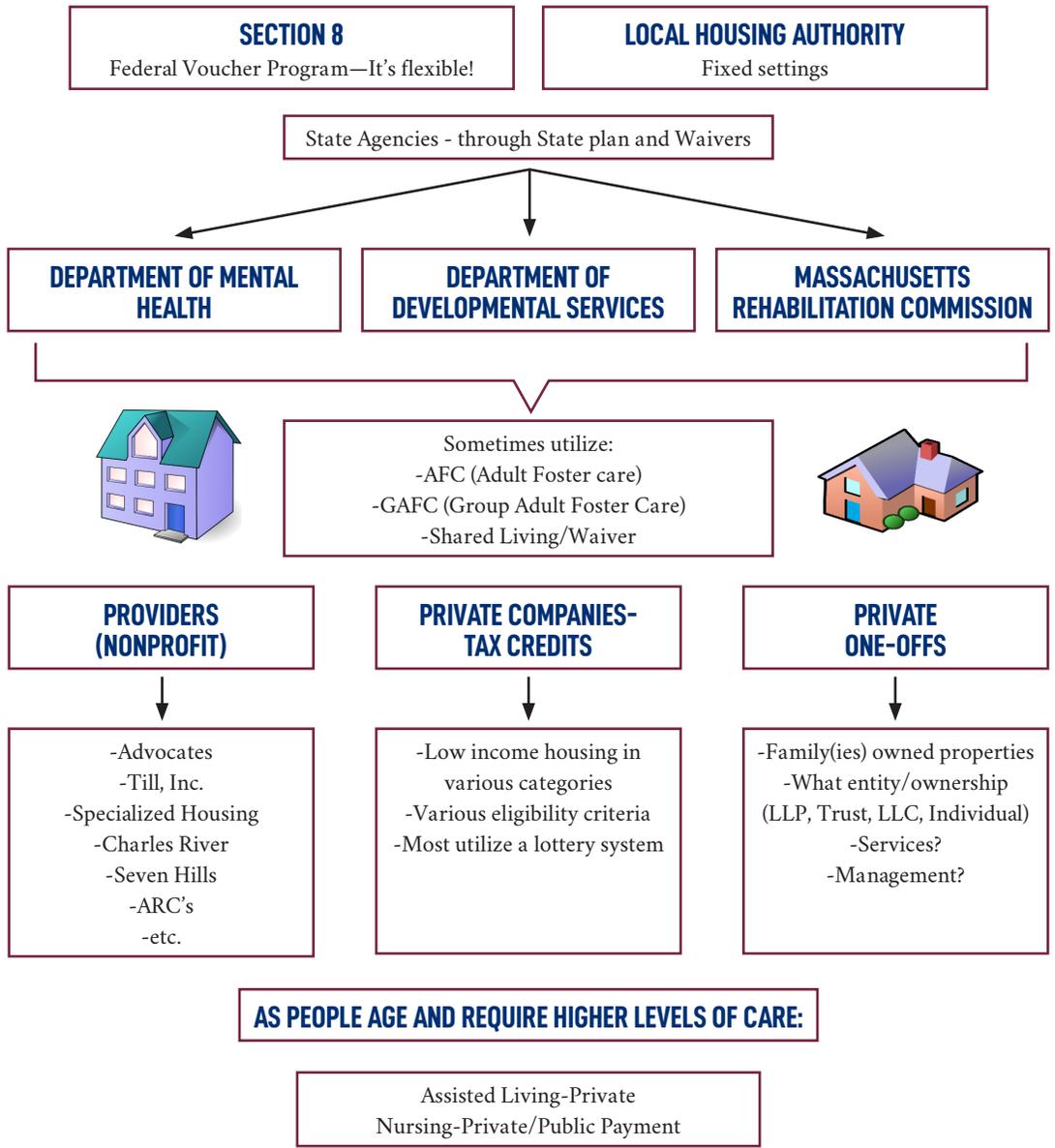
Paying for residential services without DDS or other state agency support means piecing together public benefits and family assistance in a unique way.

Some sources of payment are:

- SSI/SSDI/wages
- Housing subsidy: section 8, MHVP
- Adult Family Care (AFC) or Personal Care Attendant (PCA)
- Group Adult Foster Care (GAFC)
- SNAP (food stamps)
- MassHealth for Day Programs and Transportation
- Family or trust contribution: (\$15,000 – \$36,000/yr)

The more people who can live together, the lower the cost.

WHERE DO PEOPLE WITH DISABILITIES LIVE? AND WHO PAYS FOR IT?



SECTION 8 HOUSING INSTRUCTIONS AND INFORMATION

There are multiple forms of subsidized housing. The most common types are public housing and rental vouchers. If an individual wanted to remain in his or her current apartment, he or she would need to apply for a rental voucher, which can be used anywhere. This type of voucher is called the HUD's federally-funded Tenant Based Voucher program, also known as Section 8. These vouchers can be used to find housing in any state and therefore are the most desirable form of subsidized housing, so the waitlists are incredibly long. Most areas in Massachusetts have an 8 to 10 years long waiting list for a voucher.

Centralized waitlist

The centralized waitlist is currently sorted by 98 local housing authorities (LHAs) in Massachusetts that receive funding for the Section 8 program. Many LHAs only receive funding for 10-50 vouchers, other larger LHAs may receive funding for 500-1000 vouchers. At this time, there are well over 10,000 applicant households on the waitlist. Not all of the applicants on the waitlist will be found eligible for a voucher when called up for screening, and a vast majority will find alternate subsidized housing long before they ever reach the top of the waitlist. The timeline currently given to most applicants seeking a Section 8 voucher is 5-10 years, but it is almost impossible to accurately estimate how long the individual will be on the waitlist before he or she is called in for screening. One of the biggest reasons it is so hard to predict is that the funding for Section 8 vouchers is entirely dependent on the federal budget and Congressional approval of funding for Section 8 program. For the past few years many LHAs have had to cut vouchers due to a lack of federal funding.

Screening

When the individual reaches the top of the waitlist he or she will be called in for screening by the LHA. Some housing authorities have very specific preferences (i.e. preferences for homeless, veterans, elderly, and victims of domestic violence) and others do not. All LHAs look at income, the housing situation at the time of screening and the criminal history of the applicant. If the applicant is determined to be eligible he or she will be given a window of time, generally 90 days, to “place” the voucher. LHAs are required by law to offer reasonable accommodations to applicants and participants with disabilities. Once the individual comes up for screening he or she can request an accommodation. For example, he or she may request that the LHA send copies of all correspondence to a third party.

Using a Section 8 Voucher

Section 8 vouchers cannot be used in every apartment. The apartment must have the correct number of bedrooms as set by the LHA, it must be inspected by the LHA and meet the housing inspection standards set by HUD, and the landlord must be willing to accept the rent set by the LHA and enter into a contract with the housing authority to that effect. The individual would then be required to go to the LHA on an annual basis for a recertification appointment and provide documentation of his or her income to the LHA. The applicant would also need to do this any time he or she experienced a change in income. Again, the individual could request reasonable accommodations as needed. For example, he or she could request a 2-bedroom apartment if there was a medically documented need for a live-in personal care attendant.

Tracking waitlist status

Due to the volume of applications received, the centralized waitlist is purged frequently. To do this, notices are sent on a biannual basis to every applicant who has not updated or accessed his or her application in the last 2 years. These notices require a response within a certain number of days or the applicant is removed from the waitlist and must reapply, thereby losing his or her previous spot on the list. The applicant should be able to avoid this by mailing in a Request for Status every year or by creating an account and logging in occasionally to check his or her status.

<http://www.section8listmass.org/>

Keep in mind that if the individual's situation changes (i.e., the landlord decides to sell the house he or she lives in) there are other forms of subsidized housing which a person could apply to, but they would require the individual to move. Also, in Massachusetts there are 8 regional Housing Consumer Education Centers (HCEC) spread across the state. They typically offer a variety of housing services and may be able to offer additional housing related services if the need ever arises. The contact information for the HCEC can be found online.

RESOURCES

Brain Injury Association of America
<http://www.biausa.org>
Advancing awareness, research, treatment, and education and improving the quality of life for all people affected by brain injury.

CHADD – The National Resource on ADHD
<http://www.chadd.org>
Improving the lives of people affected by ADHD.

CURE – Citizens United for Research in Epilepsy
<https://www.cureepilepsy.org>
Seeking to cure epilepsy by identifying and funding research, and challenging scientists worldwide to collaborate and innovate in pursuit of this goal.

Disabled American Veterans
<https://www.dav.org>
Empowering veterans to lead high-quality lives with respect and dignity.

Easter Seals
<http://www.easterseals.com>
Providing services, ed
disabilities

LEGAL ASSISTANCE

Disability Law Center, Inc.

<http://www.dlc-ma.org>

Providing legal advocacy on disability issues that promote the fundamental rights of all people with disabilities to participate fully and equally in the social and economic life of Massachusetts.

Massachusetts Advocates for Children

<http://massadvocates.org>

Hotline: (617) 357-8431 ext. 3224

A voice for children who face significant barriers to equal educational and life opportunities, particularly those who have disabilities, are low-income and/or are racially, culturally, or linguistically diverse.

Massachusetts Bar Association – Lawyer Referral Service –

<http://www.masslawhelp.com/estate-planning.aspx>

Scroll down to Elder Law section and click on the link to view:

MBA's 2017 Taking Control of your Future: A Legal Checkup

Massachusetts Guardianship Association

<http://www.massguardianshipassociation.org>

Offering information and resources to individuals, families and professionals on guardianships and conservatorships.

Mass Legal Help

<http://www.masslegalhelp.org/disability>

Promoting justice in Massachusetts by providing legal information including information about disability laws.

National Academy of Elder Law Attorneys (NAELA)

<https://www.naela.org/>

Consists of attorneys who are experienced in working with the legal problems of aging Americans and individuals of all ages with disabilities.

MassNAELA

<https://massnaela.com>

The Massachusetts chapter of NAELA.

You can find member attorneys near you on the website.

Probate and Family Court Department

<http://www.mass.gov/courts/court-info/trial-court/pfc>

Information and forms for matters within the jurisdiction of the Probate and Family Court, including guardianships and conservatorships.

Volunteer Lawyers Project of the Boston Bar Association

<https://www.vlpnet.org>

Delivering free civil legal services to eligible clients in the Greater Boston area, including individual representation for guardianships and guardianship clinics in Probate and Family Courts.

ADVOCACY ORGANIZATIONS

Alexander Graham Bell Association for the Deaf and Hard of Hearing

<http://www.agbell.org>

Helping families, health care providers and education professionals to understand childhood hearing loss and the importance of early diagnosis and intervention.

American Chronic Pain Association

<https://theacpa.org>

Facilitating peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain, and raising awareness among the health care community, policy makers, and the public at large about issues of living with chronic pain.

American Council of the Blind

<http://www.acb.org>

Striving to increase the independence, security, equality of opportunity, and quality of life for all blind and visually-impaired people.

The ARC of Massachusetts

<http://thearcofmass.org>

Enhancing the lives of people with intellectual and developmental disabilities, including autism, and their families, through advocacy for community support and services that foster social inclusion, self-determination and equity across all aspects of society.

The ARC of the United States

<http://www.thearc.org>

Promoting and protecting the human rights of people with disabilities and actively supporting their full inclusion and participation in the community throughout their lifetimes.

The Autism Society of America

<http://www.autism-society.org>

Improving the lives of all affected by autism through a nationwide network of Affiliates.

Brain Injury Association of America

<http://www.biausa.org>

Advancing awareness, research, treatment, and education and improving the quality of life for all people affected by brain injury.

Centers for Independent Living

<https://www.mass.gov/independent-living-centers>

There are eleven Centers for Independent Living throughout Massachusetts. These local centers provide services to empower people with disabilities with the practical skills and self-confidence to take control of their lives and become active members of the communities in which they live.

CHADD – The National Resource on ADHD

<http://www.chadd.org>

Improving the lives of people affected by ADHD.

CURE – Citizens United for Research in Epilepsy

<https://www.cureepilepsy.org>

Seeking to cure epilepsy by identifying and funding research, and challenging scientists worldwide to collaborate and innovate in pursuit of this goal.

Disabled American Veterans

<https://www.dav.org>

Empowering veterans to lead high-quality lives with respect and dignity.

Easter Seals

<http://www.easterseals.com>

Providing services, education, outreach and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities.

The Epilepsy Foundation

<http://www.epilepsy.com>

Leading the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

March of Dimes

<http://www.marchofdimes.org>

Improving the health of babies by preventing birth defects, premature birth and infant mortality.

Massachusetts Advocates Standing Strong

<https://ma-advocates.org>

Self-advocates in Massachusetts working together to empower themselves through education to improve and enrich lives.

Massachusetts Families Organizing for Change

<http://mfoc.org>

Providing information and assistance to families, providing leadership training, and holding regular regional and statewide meetings for families and individuals living within Massachusetts.

Massachusetts Medical Orders for Life-Sustaining Treatment

<http://www.molst-ma.org>

Providing information on Massachusetts Medical Orders for Life-Sustaining Treatment.

National Alliance for the Mentally Ill

<https://www.nami.org>

Dedicated to building better lives for the millions of Americans affected by mental illness.

National Association of Councils on Developmental Disabilities

<http://nacdd.org>

National association for the 56 Councils on Developmental Disabilities across the United States and its territories.

National Down Syndrome Society

<http://www.ndss.org>

Advocating for the rights of all individuals with Down syndrome, and envisioning a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize

their life aspirations and become valued members of welcoming communities.

National Fragile X Foundation

<https://fragilex.org>

Seeking to raise awareness, build community and support research to find a cure for Fragile X syndrome.

National Gaucher Foundation

<http://www.gaucherdisease.org>

Dedicated to serving patients with Gaucher disease and their families. Through financial support, educational programming, patient services, and collaboration with medical professionals, this Foundation seeks to empower Gaucher patients to live better.

New England ADA Center

<http://www.newenglandada.org>

Hotline: 1 (800) 949-4232 (V/TTY)

Providing information, guidance and training on the Americans with Disabilities Act (ADA), and accessible information technology to individuals living in New England. Maintaining a toll-free V/TTY information line staffed by people who can answer questions about the ADA and accessible IT.

Prader-Willi Syndrome Association (USA)

<http://www.pwsausa.org>

Raising awareness, offering support, providing education and advocacy, and promoting and funding research to enhance the quality of life of those affected by Prader-Willi syndrome.

Rettsyndrome.org

<https://www.rettsyndrome.org>

Accelerating full spectrum research to cure Rett syndrome and empower families with information, knowledge, and connectivity.

Spina Bifida Association

<http://www.spinabifidaassociation.org>

Promoting the prevention of Spina Bifida and enhancing the lives of all affected.

United Cerebral Palsy

<http://www.ucp.org>

Advancing the independence, productivity and full citizenship of people with disabilities through an affiliate network.

United Spinal Association

<http://www.spinalcord.org>

Enhancing the quality of life of all people living with spinal cord injuries and disorders.

GOVERNMENT AGENCIES

Disabled Persons Protection Commission

<http://www.mass.gov/dppc>

Phone: (617) 727-6465
(888) 822-0350 V/TTY

Protecting adults with disabilities from the abusive acts or omissions of their caregivers through investigation oversight, public awareness and prevention.

Executive Office of Elder Affairs

<http://www.mass.gov/elders/healthcare>

Information on health care available to older adults.

Executive Office of Health & Human Services

<http://www.mass.gov/eohhs/gov/departments/masshealth/>

Information about the MassHealth program.

Massachusetts Attorney General's Office

<http://www.mass.gov/ago/consumer-resources/consumer-information/scams-and-identity-theft>

Information about scams and identity theft.

Mass 211

<http://mass211.org>

Connecting residents to information about critical health and human services available in the community.

Massachusetts Commission Against Discrimination

<http://www.mass.gov/mcad>

Investigating, prosecuting, adjudicating and resolving cases of discrimination based upon disability, race, color, national origin, creed, gender, gender identity, sexual orientation, and age.

Massachusetts Department of Housing and Community Development

<https://www.mass.gov/orgs/housing-and-community-development>

Providing affordable housing options, financial assistance, and other support to Massachusetts communities.

Massachusetts Developmental Disabilities Council

<http://www.mass.gov/anf/employment-equal-access-disability/oversight-agencies/mddc>

Providing opportunities for people with developmental disabilities and their families to enhance independence, productivity and inclusion.

Massachusetts Office on Disability

<http://www.mass.gov/anf/employment-equal-access-disability/oversight-agencies/mod>
Working toward the full and equal participation of all people with disabilities in all aspects of life by working to advance legal rights, maximum opportunities, supportive services, accommodations and accessibility in a manner that fosters dignity and self-determination.

Massachusetts Rehabilitation Commission

<https://www.mass.gov/orgs/massachusetts-rehabilitation-commission-0>
The Massachusetts Rehabilitation Commission (MRC) helps individuals with disabilities to live and work independently. MRC is responsible for Vocational Rehabilitation, Community Living and eligibility determination for the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) federal benefits programs.

Massachusetts – Section 8 Housing Choice Voucher Centralized Waiting List

<http://www.section8listmass.org>
The Section 8 housing choice voucher program is the federal government’s major program for assisting very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market.

MassHealth

<http://www.mass.gov/eohhs/gov/departments/masshealth>
MassHealth is the Medicaid program for Massachusetts providing health benefits and assistance for those with low income.

Medicare

<https://www.medicare.gov>
The official government site for providing information on health and financial safety for those 65 and older or those declared disabled.

Social Security Administration

<https://www.ssa.gov>
Providing retirement, disability and survivor’s benefits.

ABOUT MASSNAELA

The Massachusetts Chapter of the National Academy of Elder Law Attorneys (MassNAELA) is a non-profit organization that was incorporated in 1992, to serve the legal profession and the public with the following mission:

- To provide information, education, networking, and assistance to Massachusetts attorneys, bar organizations, and other individuals or groups advising elderly clients, clients with special needs and their families;
- To promote high standards of technical expertise and ethical awareness among attorneys, bar organizations and other individuals or groups engaged in the practice of advising elderly clients, clients with special needs and their families;
- To develop public awareness and advocate for the benefit of the elderly, those with special needs and their families, by promoting public policies that support our mission; and
- To encourage involvement and enhance membership in, and to promote networking among members of the National Academy of Elder Law Attorneys.

MassNAELA is a voluntary association whose members consist of a dedicated group of elder law and special needs attorneys across the Commonwealth of Massachusetts.

MISSION STATEMENT

The Mission of MassNAELA is to establish MassNAELA members as the premier providers of legal advocacy, guidance and services in Massachusetts to enhance the lives of people with disabilities, special needs and people as they age.

MassNAELA's further mission is to promote the highest standards of technical expertise while maintaining ethical awareness among its members who represent the most frail and vulnerable individuals.

THANK YOU

A special thank you to all the contributors and proofreaders of this of this advocacy toolkit. Our anticipated ten page toolkit has grown to a more than forty page booklet. Thank you for the many hours you have all so generously given to bring the topic of special needs advocacy to the forefront of our discussions and to create a comprehensive resource for colleagues and clients.

DISCLAIMER

This Toolkit is provided as a public service and is not intended as legal advice. Such advice should be obtained from a qualified special needs attorney.

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