

SPECIAL NEEDS ADVOCACY TOOLKIT

Steps to a Better Future
SECOND EDITION



MassNAELA[®]
National Academy of Elder Law Attorneys
Massachusetts Chapter

*Leading the Way in Special Needs and Elder Law in Massachusetts*SM

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

TABLE OF CONTENTS

3	Preface to the Second Edition
5	Introduction
11	Educational Advocacy
	11 Early Intervention
	12 Educational Entitlements
13	Medical Advocacy for Persons Over the Age of 18
	13 Guardianship
	14 Health Care Proxy
	14 HIPAA Authorization Form
	14 Medical Release
15	Financial Advocacy
	15 Joint Bank Account
	15 Representative Payee
	16 Power of Attorney
	16 ABLE Account
	16 First-party Special Needs Trust
	17 Third-party Special Needs Trusts
	18 Conservatorship
19	Medical Insurance
	19 Private Health Insurance
	20 Public Assistance Programs
	22 Self-Funded / Self-Insured Plans
23	Massachusetts Agencies that Provide Services
	23 Department of Developmental Services
	26 Department of Mental Health
	30 Massachusetts Rehabilitation Commission
31	Federal Programs that Pay Cash Benefits
	31 Supplemental Security Income
	33 Social Security Disability Insurance
35	Housing
	35 Where Adults with Disabilities Live and Who Pays for It
	37 Section 8 Housing Instructions and Information
39	Resources
	39 Support and Legal Services
	43 Advocacy Organizations
	46 Government Agencies

PREFACE TO THE SECOND EDITION



While the Second Edition of our Toolkit coincides with a time of many challenges due to the COVID-19 pandemic, it also marks a time of positive change and opportunity for people with disabilities in the United States. National attention and federal funds are being directed towards the disability community in an unprecedented way. Although not yet finalized, several proposed laws and regulations seek to improve services and increase benefits for individuals with disabilities. In addition, the topics of guardianship and conservatorship are receiving national media attention, and related state laws are undergoing revision. Here are some of the highlights as of the time of publication.

PROPOSED LEGISLATION - SECOND RECONCILIATION PACKAGE

MEDICAID

- The proposed Better Care Better Jobs Act would provide up to \$400 billion in funding for home and community-based services (HCBS).

MEDICARE

- Coverage of dental/vision/hearing
- Medicare to be provided now at age 60
- Government drug price negotiations

SUPPLEMENTAL SECURITY INCOME (SSI)

- The proposed SSI Restoration Act would increase the SSI asset limit from \$2,000 to \$10,000. The proposed legislation would also end the In-kind Support and Maintenance (ISM) penalty, and allow married couples to receive SSI benefits equaling twice the individual SSI benefit, rather than the reduced marriage penalty rate.

PROPOSED REGULATIONS

HOUSING

- HUD issued final rules implementing parts of the Housing Opportunity Through Modernization Act of 2016 (HOTMA). Several of these rules are favorable to the disability community. For example, distributions from special needs trusts (SNTs) should no longer be counted as income for Section 8 recipients.

SOCIAL SECURITY

- SSA Proposed rule: Stop Counting Food When Calculating In-kind Support and Maintenance. The Social Security Administration plans to propose that the definition of In-kind Support and Maintenance (ISM) no longer consider food expenses as a source of ISM.
- SSA Proposed rule: Reducing the Burden on Families. This rule implements Section 102 of the Strengthening Protections for Social Security Beneficiaries Act of 2018, which exempts certain representative payees, such as parents, from annual accounting requirements.

RETIREMENT BENEFITS

- IRS Proposed rule: Guidance on 401(a)(9) Required Minimum Distributions. This covers Section 401 of the SECURE Act, which mandates stricter distribution requirements for inherited retirement accounts. However, these rules exempt inherited retirement accounts left to qualifying supplemental needs trusts from the new stricter distribution requirements.

GUARDIANSHIP/CONSERVATORSHIP

- The Britney Spears case has penetrated nearly all aspects of media from *Teen Vogue* to the *New York Times*. This is an exciting time for change and advancement in the way we, as a society, look at guardianship and decision-making for the disabled in our communities.
- In May 2021, the National Guardianship Network proposed a number of recommendations to improve and reform the adult guardianship system in the United States. Many state agencies, court systems, and advocacy organizations, such as the National Academy of Elder Law Attorneys (NAELA), are reviewing these recommendations and considering signing onto them and implementing them in their respective states.
- In February 2021, a bill was introduced in the Massachusetts legislature to enable individuals with special needs to sign contracts called “supported decision-making agreements.” These agreements allow a person or a group of people (the “supporter”) to perform specific tasks for a special needs individual, and can be relied upon by outside parties. The supporter is authorized to be involved with the day-to-day decisions regarding support, care, education, health, and welfare of the special needs individual. This is different from a health care agent under a health care proxy or a guardian who makes decisions on behalf of the special needs individual. Note that as of the publication of this toolkit the supported decision-making bill has not passed the Massachusetts legislature.

While many of these changes are not yet in place at the federal or state level, it is encouraging to see favorable movement on several issues critical to the disability community. Much of the momentum behind these changes is due to the persistent and dedicated advocacy of disability rights organizations, including NAELA. Together, NAELA and MassNAELA will strive to keep the disability community informed as relevant laws and regulations evolve.

MassNAELA acknowledges and thanks the national leadership of NAELA, and especially David Goldfarb, NAELA’s Director of Advocacy, who compiled most of this information.

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, cause

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 individuals 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, 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 get 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 from infancy until 22 years of age.

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 (IFSP) to describe the services that are needed by the child and family, and how these services 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 to facilitate the developmental progress of eligible children. Services may include, but are not limited to: assistive technology, audiology services, health services (e.g., 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 therapy, vision services (e.g., 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

Educational Entitlements (ages 3-21)

Children ages 3 through 21 with disabilities severe enough to negatively affect learning are entitled to a Free Appropriate Public Education (FAPE). This is 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. This is known as the Child Find mandate. State regulations set out timelines and the methods to accomplish this, as well as administrative procedures to resolve any disputes.

For students with qualifying disabilities, school districts must annually develop a written Individualized Education Program (IEP) that outlines the services to be provided with measurable goals and accommodations that allow him or her to access the curriculum. Federal law requires that each child must receive a program that meets his or her unique and individual needs in the least restrictive environment (LRE). For some children, the IEP might involve classroom modifications, individual instruction, therapy, or other related services. 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 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. Progress reports must be given every time report cards are distributed. Evaluations and other records can be helpful later in life to determine eligibility for adult services and other government assistance programs, so it is a good idea to keep these records.

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 their child turns 18, the parents stop being their child's legal guardian. Consequently, parents may no longer be able to receive information from the health care team about their child. If you are advocating for a person with special needs who 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 after attaining the age of 18. Therefore if, due to a disability, a person is not capable of making his or her own decisions, it is necessary to secure the judicial appointment of a guardian for him or her. There is no assumption of incapacity, even in the most obvious of cases. In Massachusetts, only a judge in our 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 legally incapacitated. The guardian's job is to make day-to-day decisions regarding support, care, education, health, and welfare. In some cases, the judge will decide, based on the evidence in the case, that the individual has the capacity to make some decisions but not all decisions. In such cases, the guardian's job will be limited to only making those decisions that the individual is unable to make on his or her own behalf.

You may want to seek out an attorney with experience in handling guardianships to guide you through the process. In some circumstances, a second attorney will be appointed to represent the incapacitated person, and it may be more important that you, as the person requesting the guardianship (called the "petitioner"), are also represented by your own counsel.

However, oftentimes 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 information sessions where volunteer attorneys can answer questions and help fill out forms.

As a side note, a guardian does not bear any risk for the incapacitated person's acts or debts, and is under no legal obligation to provide a home or direct care to the incapacitated person. A guardian does have regular and ongoing reporting requirements to the court. An attorney who specializes in elder law or special needs law can help you comply with those requirements.

HEALTH CARE PROXY

A health care proxy is a legal document that authorizes a health care agent to make health care decisions on behalf of an individual if or when the individual is unable to do so, including decisions about life-sustaining treatment. A person with special needs or a disability can complete a health care proxy if he or she has the capacity to do so.

It is imperative that an individual with capacity sign a health care proxy upon reaching age 18 for two main reasons. First, having a health care proxy allows the health care agent to participate in the decision-making process with the individual, so that the disabled individual can make the most informed decision. Second, if the disabled individual's health declines to the point where he or she becomes unable to make medical decisions, the agent will be able to make medical decisions on behalf of the individual and will have more knowledge of what he or she would have wanted.

It is a good idea to have an attorney prepare the health care proxy because the attorney can determine whether the individual has the capacity to sign the document. Broadly speaking, capacity requires an understanding of what the document does, and who is being appointed. Individuals under the age of 18 (minors) do not have the capacity to sign a health care proxy.

For children with special needs, it is recommended that families start discussing the appointment of a health care agent with the child when he or she is under the age of 18, and seek out an attorney before the child turns 18. That way, when the child turns 18, the health care proxy can be prepared, signed, and put into legal effect as quickly as possible.

HIPAA AUTHORIZATION FORM

The Health Insurance Portability and Accountability Act of 1996, known as HIPAA, is the primary federal regulation that protects the privacy of an individual's health care records. When an individual reaches the age of 18, a parent or guardian no longer has the authority to review the individual's medical records. A person with special needs or a disability can complete a HIPAA Authorization if he or she has the capacity to do so. Executing a HIPAA Authorization will give the individual's trusted agent(s) the ability to review his or her medical records so that the agent(s) can access medical records and consult with health care providers on behalf of, or in the company of, the individual.

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 his or her behalf.



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 given to, or withheld from, the disabled individual.

Joint Bank Account

When a disabled or 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 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. A joint owner is not authorized to do whatever they want with the disabled person's money.

Representative Payee

If the disabled or 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 shall be appointed to receive the government benefit. Note, a Power of Attorney is not recognized by the SSA.

Power of Attorney

A Durable Power of Attorney is a document that allows an individual (the “principal”) to appoint an agent (also known as “attorney-in-fact”) 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 a Durable Power of Attorney so that an agent can be appointed to manage his or her financial affairs. If the disabled individual is 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 before the individual’s 26th birthday. The individual must provide evidence that he or she is blind or disabled in one of the following ways:

- receive SSI and/or SSDI benefits based on blindness or disability; or
- certify that he or she is blind or disabled (as defined by Social Security) and have a written diagnosis of his or her impairment from his or her licensed health care provider.

There are limits to the annual contributions to, and maximum allowable balance of, an ABLE account. Furthermore, 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. Qualified disability expenses may include costs related to education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative and other expenses that help improve the disabled individual’s health, independence, and 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, an authorized signatory must be designated on the account. An authorized signatory must be a person selected by the eligible individual, an attorney-in-fact, guardian or conservator, spouse, parent, sibling, grandparent, or Representative Payee designated by the Social Security Administration. The authorized signatory may not have, or acquire, any beneficial interest in the account and must administer the account for the benefit of the account owner.

The ABLE National Resource Center offers independent information about all federal and state related ABLE programs. To find out more or open an account, please visit the website at www.ablenrc.org.

First-party Special Needs Trusts (SNTs)

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. It is also at times called a 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. To protect the public benefits, the first-party SNT must have a Medicaid payback provision. When the disabled person passes away any assets remaining in the trust must first be used to pay back or reimburse every state that has paid Medicaid benefits on behalf of the disabled individual before the assets in the trust can be distributed to other beneficiaries.

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 while also receiving public benefits, 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 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 third-party 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 third-party 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 an attorney who is familiar with disability services and programs in your state.

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

Funding a third-party SNT with retirement assets is a beneficial way to leave retirement assets for a disabled individual. In fact, certain third-party SNTs for disabled or chronically ill individuals enjoy more favorable treatment than other beneficiaries of retirement assets. This is due to the passage of the SECURE Act of 2019, which changed the rules about inherited retirement assets. Under SECURE, if a properly drafted third-party SNT is established for the benefit of a disabled or chronically ill individual and the SNT is named as the beneficiary of a retirement account, the required minimum distributions payable to the SNT may be withdrawn over the disabled individual's life expectancy, instead of within a compressed ten-year time bracket. The distributions from the retirement account received by the third-party SNT can be held in trust for the benefit of the disabled beneficiary based on the terms of the SNT.

Trust funds can be used to pay for 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, it is preferable to utilize the other options discussed above because of the legal costs 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 his or her own financial affairs. Similar to guardianships discussed earlier in this Toolkit, the Probate and Family Court appoints the conservator. Since it is a formal legal appointment and the court retains oversight over the estate of the incompetent individual, meticulous record-keeping is necessary and 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 guardianships and conservatorships to guide you through the legal process.

MEDICAL INSURANCE



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

1. Private Health Insurance (including group health plans);
2. Public Health Assistance Programs (Medicaid and Medicare); and
3. 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 one 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.massairc.org).

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

MEDICAID

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 needs of the member. One key difference to this notion is for people who need long term services and supports (LTSS). Long term services and supports consist of:

- institutional or nursing home level care;
- some community based services; and
- home and community-based waiver services (HCBS), 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;
- Early and Periodic Screening, Diagnosis and Treatment (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 Aids • Hospice • Transportation • Private Duty Nursing services • Personal Care services • Clinic services • Therapies (ST, OT & PT) • Intermediate care (ICF/MR) • In-patient psychiatric care for under 21 & older than 65.

Among the mandatory Medicaid services contained in the Medicaid State 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, the disabled person’s 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 the disabled person’s 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 elderly and disabled individuals with care in the home and community as an alternative to institutional care.

In Massachusetts, we have an acquired brain injury waiver (ABI), a Moving Forward Plan (MFP) 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

Medicare is a partner program to Social Security. Medicare provides health insurance to those who are 65 years and older, and to those under age 65 who are disabled and have received Social Security Disability Insurance (SSDI) benefits for a minimum of 24 months. Medicare is divided into two parts: Part A and Part B. Part A covers hospital and limited nursing care. Part B, which requires an extra premium, covers outpatient 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.

As with private insurance policies, there may be provisions 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 (DDS) 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 FOR ADULTS (AGE 22 OR OLDER)

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, and the intellectual disability originates prior to age 18.

ELIGIBILITY FOR CHILDREN (BIRTH THROUGH AGE 21)

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 Spectrum Disorder, Smith-Magenis 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, MD, 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: <https://www.mass.gov/dds-eligibility-services#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 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 an individual's needs and capabilities along with the strengths and needs of the individual's caregivers. The MASSCAP consists of the following three parts.

1. 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 means "never or rarely does well" in that area, and three points means "does very well" in that area. This information is then entered into the ICAP application to determine the total ICAP score.
2. 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.
3. 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 a DDS eligibility specialist with training and experience in the field of intellectual disabilities who will make a decision based upon professional judgment.

The MASSCAP process will typically provide the information necessary for DDS to determine whether an individual has an assessed need for a requested service. In certain circumstances, DDS 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 of DDS. 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 DDS 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 DDS 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, DDS 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 DDS in assessing the support needs of individuals found eligible for DDS adult services as persons with intellectual and developmental disabilities (IDD). SIS helps determine the supports necessary for eligible individuals with IDD to succeed.

A valid assessment requires the participation of at least two respondents who have known the individual for at least three months, and preferably 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 counsel be retained for the proceedings.

NICKY'S LAW - ABUSE REGISTRY

On February 13, 2020, after six years of advocacy, Nicky's Law finally passed. This is a major milestone and substantial victory for the disability community. The new law creates a registry that lists the names of providers or caregivers who have committed acts of substantiated abuse that have resulted in serious physical injury or serious emotional injury for adults served by the Department of Developmental Services (DDS). The registry is established and maintained by the Disabled Persons Protection Commission (DPPC). Effective January 31, 2021, any individual listed on the registry cannot be hired or work for DDS or any of its licensed or funded providers throughout the state.

The DPPC will make the finding of the registrable abuse after an investigation and opportunity to appeal. A care provider is a person who is employed by, or contracts with, DDS or an Employer who provides services or treatment to persons with intellectual or developmental disabilities between the ages of 18-59. It includes current and prospective caretakers, volunteers, interns, work-study participants or any other similar unpaid positions, in any program licensed, contracted or funded by DDS.

DEPARTMENT OF MENTAL HEALTH

The Department of Mental Health (DMH) is an agency within the Executive Office of Health and Human Services. As the State Mental Health Authority, DMH 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. DMH establishes standards to ensure effective and competent care to promote recovery. DMH 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. 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 resource guides that help consumers, families and the general public find information about DMH and their services, as well as other statewide services and programs in the mental health community.

<https://www.mass.gov/service-details/dmh-resource-guides>

- 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.

<https://www.mass.gov/doc/dmh-resource-guide/download>

- b.) The Emergency Services Programs (ESP) Resource Guide lists all ESPs statewide, their location, corresponding cities and town and toll-free crisis number.

<https://www.masspartnership.com/pdf/ESPFlyerIndividualsandfamilies.pdf>

- c.) 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.
<https://www.mass.gov/handbook/young-adult-resource-guide>

- d.) 2019 DMH Multicultural Mental Health Resource Guide contains information about organizations in the Commonwealth that offer culturally and linguistically appropriate mental health and related services for communities of color, LGBTQ community, immigrants, and refugees.
<https://www.mass.gov/lists/dmh-multicultural-mental-health-resource-directory>

- e.) Extreme Risk Protective Order Resource Guide contains information on resources for individuals seeking an extreme risk protective order, or who had an extreme risk protective order issued against them. The resources include crisis intervention, mental health, substance misuse, counseling services, interpreter services, civil commitment guidance, and other relevant services.
<https://www.mass.gov/handbook/extreme-risk-guide> .

ELIGIBILITY

DMH is responsible for providing or arranging for services to adults with serious and long term mental illness, and children and youth with serious emotional disturbance, who are domiciled in Massachusetts and who are determined to meet clinical criteria and to need services. Services are provided along a continuum of intensity and are authorized in accordance with a person's specific needs. DMH service planning activities include provisions for transition between levels of intensity as a person's needs change. However, a person will only be authorized to receive DMH community services if DMH has the available capacity and resources to provide the DMH community service.

There are three general categories that people will fall into: Adult, Children and Youth, and Transitional Age Youth.

ADULT

For purposes of DMH eligibility, an adult is defined as an individual who is 22 years of age or older. To meet the clinical criteria to receive DMH services, an adult must have a serious and persistent mental illness that is the primary cause of functional impairment that substantially interferes with or limits the individual performance of one or more major life activities and is expected to do so in the succeeding year. The adult must also meet the clinical criteria for one of the following disorders: Schizophrenia Spectrum, and other Psychotic Disorders; Bipolar and Depressive Disorders; Anxiety Disorders; Dissociative Disorders; Feeding and Eating disorders; Borderline Personality Disorder; Obsessive-compulsive and Related Disorders; Trauma and Stressor Related Disorders.

As described above, functional impairment in a person with a co-occurring disorder does not have to be attributed solely to an individual's qualifying mental disorder. Major life activities include basic daily living skills (e.g., eating, bathing, dressing, maintaining a household, managing money, accessing generic community services, taking prescribed medication) and functioning in social, family, and vocational/ educational contexts. Risk of harm to self or others is also recognized as an index of functional impairment.

CHILDREN AND YOUTH

For purposes of DMH eligibility, a child or youth is defined as an individual younger than 22 years at the time of application who has a serious emotional disturbance that meets diagnostic criteria for a diagnosis specified with the Diagnostic and Statistical Manual of Mental Disorders, which is the primary cause of functional impairment that substantially interferes with or limits the individual's performance of one or more major life activities, and is expected to do so in the succeeding year.

Difficulties resulting from a serious emotional disturbance may substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative or adaptive skills. Risk of harm to self or others is also recognized as an index of functional impairment. Functional impairment of episodic, recurrent and continuous duration is included unless it is a temporary and expected response to stressful events in the child or adolescent's environment.

TRANSITIONAL AGE YOUTH

For transition planning purposes, the determination of whether an individual who is 18 through 21 years of age at the time of application meets clinical criteria for youth shall include a consideration of whether the individual is likely to meet the clinical criteria for adults. A youth who is receiving DMH services shall be referred for determination as an Adult no later than 12 months before his or her 22nd birthday.

APPLICATION PROCESS

There is one application form which is referred to as a Request for DMH Services and it is available at this link: <https://www.mass.gov/doc/fillable-dmh-application-for-services-pdf/download>.

In addition to the Request for DMH Services application form, an applicant must also provide a DMH Service Authorization Determination and Authorization(s) for Release of Information for all current providers, including any hospitals where the applicant may have been treated. Both of these forms are part of the above link. DMH needs information such as outpatient psychiatric records and testing; admission and discharge reports or summaries; clinical assessments; neuropsychological testing; treatment plans; and Individualized Educational Plans. It is best to have a mental health clinician, preferably the treating psychiatrist, complete the DMH application.

The application is filed with the DMH area office that covers the town where the applicant lives. A list of the towns is available at the DMH website and contained in the above noted link. Within five (5) days of receipt of a Request for DMH Services application, DMH will contact the applicant or guardian to acknowledge receipt of the application. Within twenty (20) business days of receipt of an application DMH shall determine whether the application is complete, and if any additional information request has not been received, and shall notify the applicant. Within 20 business days of receipt of the completed application DMH shall determine whether the individual meets the clinical criteria set forth in the regulations.

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. A decision will be made within 90 days of DMH receiving the application, based upon the information that is available.

AUTHORIZATION FOR RELEASE OF INFORMATION

An Authorization for the Release of Information (2-way) is included with the Request for DMH Services. Applicants will need to submit a separate Authorization for Release of Information for each person, agency or facility with whom the applicant authorizes DMH to exchange 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, called 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>

MASSACHUSETTS REHABILITATION COMMISSION

The Massachusetts Rehabilitation Commission (MRC) provides vocational and related services to people with disabilities. MRC services are provided to adults, but MRC can also be accessed by students with disabilities to begin transition services while they are still in high school, with some services such as pre-employment transition services starting as early as fourteen years old.

MRC's vocational services currently include the following: evaluations, interest and aptitude testing, college or vocational training, job placement assistance, counseling and guidance, internship opportunities, supported employment, skills training, assistive technology, youth leadership networking, job coaching, and tutoring. MRC also offers tuition assistance and limited housing, and can make referrals for technology acquisition loans. In addition, MRC offers an array of services through the Statewide Head Injury Program (SHIP).

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.

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. MRC has 60 days from the date of application to determine if an applicant is eligible for services.

MRC does not serve individuals who are blind. Legally blind individuals can obtain employment and social rehabilitation services through the Massachusetts Commission for the Blind: <https://www.mass.gov/orgs/massachusetts-commission-for-the-blind>

More information about MRC can be found on MRC's website: <https://www.mass.gov/orgs/massachusetts-rehabilitation-commission-0>

In addition, the Federation for Children with Special Needs (<https://fcsn.org>) provides "A Family Guide to Transition Services," available here: https://fcsn.org/transition_guide/english.pdf

SOCIAL SECURITY ADMINISTRATION

FEDERAL PROGRAMS THAT PAY CASH BENEFITS

Supplemental Security Income (SSI)

SSI is a federal “safety net” program that pays a subsistence amount of income every month. In order to qualify, someone who is 18-65 years of age must:

- be blind or otherwise disabled according to Social Security’s standards;
- have low income, which, for an individual, is generally no more than \$1,673/month if the income is from work (\$2,190/month for a blind person), and no more than \$814 if the income is not from work; 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. 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 an eligible individual in 2021 is \$794/month. Eligible individuals who live in Massachusetts may receive a small state supplement, and they will get two checks every month: one from the federal government and one from the state. Massachusetts residents who receive SSI automatically receive MassHealth (Medicaid) free of charge.

RESOURCE LIMITS

The SSI program has a \$2,000 resource limit for individuals (\$3,000 for a couple) that is strictly enforced. The resources that Social Security counts toward the individual’s \$2,000 limit include:

- checking and savings accounts;
- savings bonds (including accrued interest);
- stocks, bonds, and mutual funds;
- UTMA (Uniform Transfers to Minors Act) accounts 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 SSI program does *not* count toward the individual's \$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, if the person seeking SSI benefits is the beneficiary of the plan but not the owner;
- funds in a special needs trust that is properly written and is being managed correctly according to the SSI rules; and
- an ABLÉ 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 "ambulate effectively," which generally means inability to walk without assistive devices that limit the use of your hands.

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 \$1,310/month. Social Security calls the ability to work and earn this level of income "substantial gainful activity," which is commonly abbreviated as "SGA."

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 \$1,930 per month to a maximum of \$7,770 per year (effective January 2021).

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, after disregarding the first \$20 of unearned income per month. Such "unearned income" includes Social Security Disability Insurance payments, a pension, an annuity, and child support.

Some types of unearned income, such as food stamps, home energy assistance, and income tax refunds, will not be counted. In addition, in 2021, Social Security decided not to count pandemic-related financial assistance, such as unemployment assistance, economic impact payments, and emergency rental assistance.

In-kind Income. A person's SSI benefits will be reduced if he or she receives any "in-kind support and maintenance" (ISM), which is food and shelter the person receives and does not pay the full value to acquire. For example, if an adult SSI 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 \$265/month). Fortunately, the

person usually will not lose more than \$265/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 first-party special needs trust, which is also sometimes referred to as a “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 SSDI benefits is to establish a work record. You must have worked long enough — and recently enough — under Social Security to qualify for disability benefits.

In general, a person must have earned 40 credits, 20 of which were earned in the last 10 years ending with the year the person became disabled (in 2021, a person earns one credit for each \$1,470.00 earned per quarter in wages or self-employment income; a person must have worked 40 quarters, not just ‘earned’ 40 x \$1,470). Younger workers may qualify with fewer credits. The credits 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 was 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 Medicare 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 benefits based upon their parent’s work record:

- a parent reaches retirement age and begins to draw Social Security retirement benefits;
- a parent becomes disabled before reaching retirement age and collects SSDI benefits; or
- a 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;
- the child's disability must prevent the child from engaging in "substantial gainful activity," known as SGA (in general, "inability to engage in SGA" means an inability to earn at least \$1,310/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);
- the child's disability must have been continuous from before the child was age 22 through the time the child is claiming benefits (if the earnings are at or above SGA level 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 credits 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 benefit 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 as other children, spouses, ex-spouses, and parents.

NO LIMITS ON ASSETS OR UNEARNED INCOME

Unlike the SSI program, 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 not be more than \$1,310/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 unearned income level for the SSI program (\$814 for an individual, in 2021), he or she can apply for SSI payments to supplement his or her SSDI benefit to bring the total benefit amount up to the maximum SSI benefit. The person would have to meet the income and asset restrictions for the SSI program (i.e., limits on earned and unearned income and no more than \$2,000 in countable resources).

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. However, 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. Unfortunately, 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 since 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 the Department of Developmental Services (DDS) and the Department of Mental Health (DMH) are the major providers of residential services (the Massachusetts Rehabilitation Commission (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 time frames 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.

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 wants 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 the 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, the individual may request that the LHA send copies of all correspondence to a third party.

USING A SECTION 8 VOUCHER

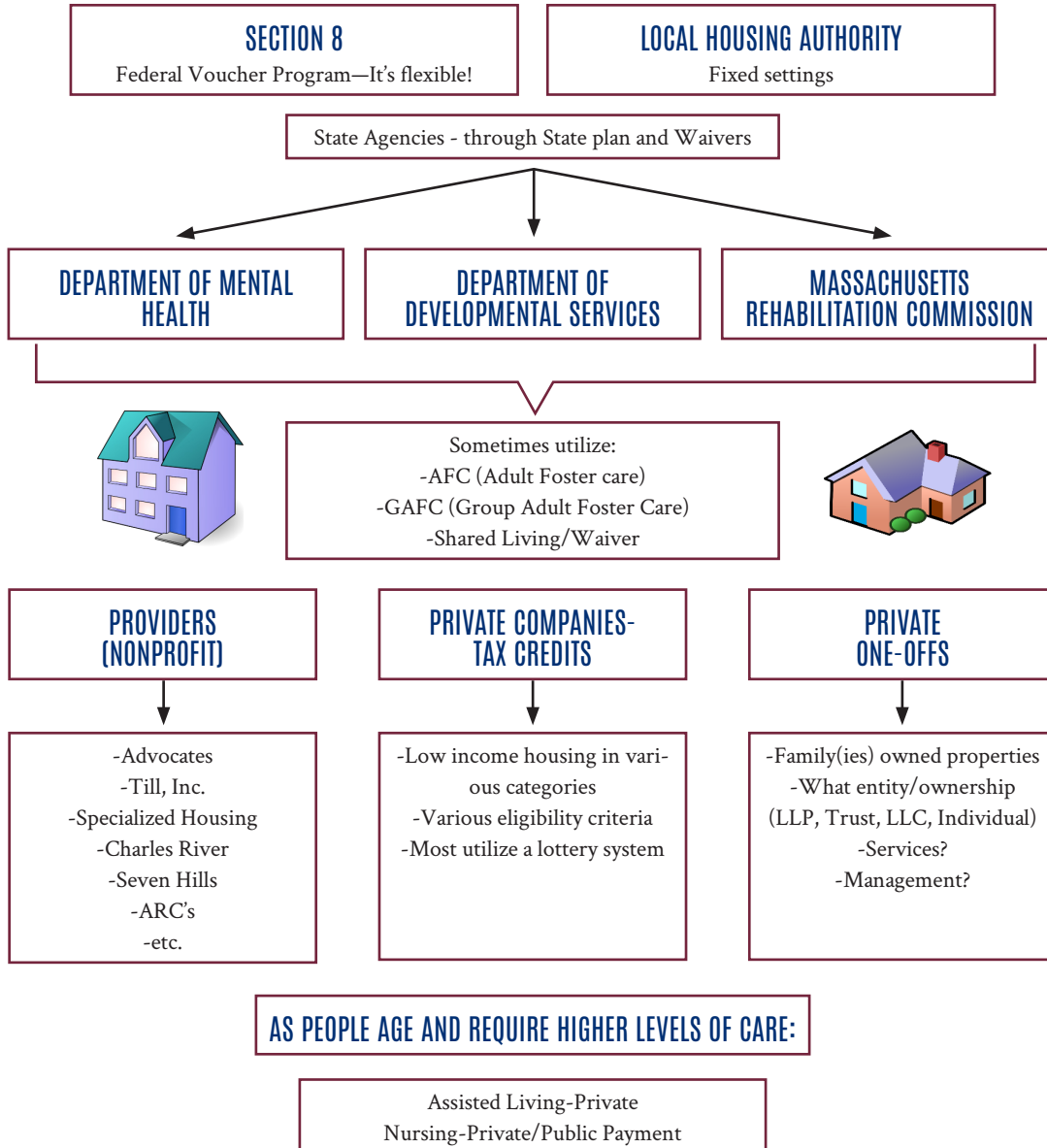
Section 8 vouchers cannot be used in every apartment. The apartment must have the correct number of bedrooms as set by the LHA, it must be inspected by the LHA and meet the housing inspection standards set by HUD, and the landlord must be willing to accept the rent set by the LHA and enter into a contract 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. See <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 eight 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 your regional HCEC can be found online: <https://www.masshousinginfo.org/>

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



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

SUPPORT AND LEGAL SERVICES

ABLE NATIONAL RESOURCE CENTER

<https://www.ablenrc.org>

Provides independent information about federal and state related ABLE programs and activities.

ADVOCATES

<https://www.advocates.org>

Partners with individuals, families, and communities to shape creative solutions to the obstacles facing people with developmental and mental health challenges.

ALZHEIMER'S ASSOCIATION

<https://www.alz.org/manh>

24-hour hotline: 800-272-3900

Provides a variety of supports, including early stage programs and services, social engagement, education programs, support groups and care consultation.

ASPERGER/AUTISM NETWORK (AANE)

<https://www.aane.org>

Provides individuals, families, and professionals with information, education, community, support and advocacy.

AUTISM ALLIANCE

<https://www.autismalliance.org>

Provides support, programs, and resources to families and individuals affected by autism spectrum disorders.

AUTISM CONNECTIONS

<https://autismconnectionsma.org/en>

The Autism Resource Center for western Massachusetts, including Hampden, Hampshire, Franklin and Berkshire counties, and the North Quabbin area. Provides support, information, and practical help for children and adults with autism and their families, friends, and professionals.

AUTISM HOUSING PATHWAYS

<https://autismhousingpathways.org>

Provides information, support and resources for families who seek to create secure, supported housing for their adult children with disabilities.

BEST BUDDIES

<https://www.bestbuddies.org/mari>

A Massachusetts and Rhode Island program that fosters one-to-one friendships between individuals with and without intellectual developmental disabilities, integrated employment, and leadership development.

BOSTON CENTER FOR INDEPENDENT LIVING

<https://bostoncil.org>

Provides peer mentoring, skills training, advocacy and transition planning to people with disabilities.

BRIDGEWELL

<https://bridgewell.org>

Provides a range of social and human services for people with disabilities and other life challenges, including recovery services, homeless and housing services, and professional development.

CENTER FOR LIVING AND WORKING

<https://www.centerlw.org>

Provides ADA Consulting, Deaf & Hard of Hearing Services, Independent Living, One Care long-term supports and services, personal care management, and youth services to empower individuals with disabilities to live as independently as possible.

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.

FAMILY TIES OF MASSACHUSETTS

<https://www.massfamilyties.org>

A program funded by, and in collaboration with, the Massachusetts Department of Public Health. Provides information, referrals, and training to families and professionals supporting children and youth with special needs.

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

<https://fcsn.org>

Provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities.

HMEA'S AUTISM RESOURCE CENTRAL

<https://www.autismresourcecentral.org>

Supports the Massachusetts Department of Developmental Services' Central-West Region. Provides education, family activities, referrals and support to families affected by Autism Spectrum Disorders (ASD). The Center also provides information on a variety of issues to assist parents and professionals.

JEWISH FAMILY & CHILDREN'S SERVICES

<https://www.jfcsboston.org/About/About-JF-CS>

Provides services and care for individuals and families by providing exceptional human services guided by Jewish traditions of social responsibility, compassion, and respect for all members of the community.

JUSTICE BRIDGE

<https://www.justice-bridge.org>

Matching unrepresented litigants with recent law school graduates who don't yet have clients.

MASSACHUSETTS ADVOCATES FOR CHILDREN

<http://massadvocates.org>

Hotline: (617) 357-8431 ext. 3224

A voice for children and youth 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 (LRS)

<https://www.masslawhelp.com>

Provides referrals to qualified Massachusetts attorneys in a variety of areas, including estate planning, government benefits and services, employment, housing, education, and consumer rights.

MASSACHUSETTS GUARDIANSHIP ASSOCIATION

<http://www.massguardianshipassociation.org>

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

MASS LEGAL HELP

<https://www.masslegalhelp.org>

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

METROWEST CENTER FOR INDEPENDENT LIVING

<https://mwcil.org>

Provides services that enable people with disabilities to live in the community.

METROWEST LEGAL SERVICES

<https://mwlegal.org>

Provides free civil legal aid to low low-income people and victims of crime who would be denied justice without free legal aid.

MASSNAELA

<https://massnaela.com>

The Massachusetts chapter of the National Academy of Elder Law Attorneys (NAELA).

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS (NAELA)

<https://www.naela.org>

A professional organization for attorneys who specialize in the legal problems of aging Americans and individuals of all ages with disabilities.

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.

SPECIALIZED HOUSING, INC.

<https://www.specializedhousing.org/home-1>

Offers independence with support for adults with disabilities through home ownership, work, an active social life, and community connections.

SPECIAL NEEDS ARTS PROGRAMS, INC.

<http://www.snaparts.org>

Provides music and art programs for people with special needs that celebrate each person's unique abilities while cultivating creative expression.

TOWARD INDEPENDENT LIVING AND LEARNING, INC. (TILL)

<https://www.tillinc.org>

Provides residential, clinical and family support services, including vocational programs and day activities for individuals living with Autism Spectrum Disorders, with and without intellectual disabilities, and their families.

VOLUNTEER LAWYERS PROJECT OF THE BOSTON BAR ASSOCIATION

<https://www.vlpnet.org>

Delivers 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.

WORK WITHOUT LIMITS

<https://workwithoutlimits.org>

An initiative of Commonwealth Medicine, the consulting and operations division of UMass Chan Medical School, whose goal is to position Massachusetts as the first state in the nation where the employment rate of people with disabilities is equal to people without disabilities. They offer programs, services, training and consultation to advance workplace disability inclusion.

ADVOCACY ORGANIZATIONS

ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF AND HARD OF HEARING

<http://www.agbell.org>

Helps 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>

Facilitates peer support and education for individuals with chronic pain and their families, and raises 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>

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

THE ARC OF MASSACHUSETTS

<http://thearcofmass.org>

Enhances 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>

Promotes and protects the human rights of people with intellectual and developmental disabilities, and actively supports their full inclusion and participation in the community throughout their lifetimes.

THE AUTISM SOCIETY OF AMERICA

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

Provides advocacy, education, information and referral, support, and community for individuals and families living with autism through a nationwide network of Affiliates at national, state and local levels.

BRAIN INJURY ASSOCIATION OF AMERICA

<http://www.biausa.org>

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

CHADD - THE NATIONAL RESOURCE ON ADHD

<http://www.chadd.org>

Provides information, support, and community for children and adults with ADHD.

CURE - CITIZENS UNITED FOR RESEARCH IN EPILEPSY

<https://www.cureepilepsy.org>

Seeks 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>

Provides resources to veterans and their families to access medical care, benefits, and employment opportunities.

EASTER SEALS

<http://www.easterseals.com>

Provides 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>

Provides community services, public education, federal and local advocacy, seizure first aid training, and research funding into new treatments and therapies.

MARCH OF DIMES

<http://www.marchofdimes.org>

Supports and advocates for the health of mothers and babies. Educates medical professionals and the public about best practices in prenatal, neonatal and pediatric care. Provides comfort and support to families in NICUs.

MASSACHUSETTS ADVOCATES STANDING STRONG

<https://ma-advocates.org>

Provides information, education and support to individuals with intellectual and developmental disabilities so that they can self-advocate.

MASSFAMILIES

<https://massfamilies.org>

MassFamilies (formerly known as Massachusetts Families Organizing for Change) provides information, assistance, and leadership training for families and individuals living with disabilities within Massachusetts.

MASSACHUSETTS MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT

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

Provides information on Massachusetts Medical Orders for Life-Sustaining Treatment (MOLST), a standardized medical order form for use by clinicians caring for patients with serious advancing illnesses.

MENTAL HEALTH LEGAL ADVISORS COMMITTEE

<http://mhlac.org>

Provides legal and policy advocacy for people with mental health challenges throughout Massachusetts.

NATIONAL ALLIANCE FOR THE MENTALLY ILL

<https://www.nami.org>

Provides advocacy, education, support and public awareness so that all individuals and families affected by mental illness can build better lives.

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. The DD Councils receive federal funding to support programs that promote self-determination, integration and inclusion for all people in the United States with developmental disabilities.

NATIONAL DOWN SYNDROME SOCIETY

<http://www.ndss.org>

Supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy, and Community Engagement.

NATIONAL FRAGILE X FOUNDATION

<https://fragilex.org>

Serves all those living with Fragile X with a focus on community, awareness, and research in the pursuit of treatments and a cure.

NATIONAL GAUCHER FOUNDATION

<http://www.gaucherdisease.org>

Empowers patients with Gaucher disease and their families through financial support, educational programming, patient services, and collaboration with medical professionals.

NEW ENGLAND ADA CENTER

<http://www.newenglandada.org>

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

Provides information, guidance and training on the Americans with Disabilities Act (ADA), and accessible information technology to individuals living in New England.

PRADER-WILLI SYNDROME ASSOCIATION (USA)

<http://www.pwsausa.org>

Empowers the PWS community through shared experiences, research, education, advocacy, and support.

RETTSYNDROME.ORG

<https://www.rettsyndrome.org>

Focuses on accelerating research to treat and cure Rett syndrome, and empowers families with information, knowledge, and connectivity.

SPINA BIFIDA ASSOCIATION

<http://www.spinabifidaassociation.org>

Promotes the prevention of Spina Bifida and enhances the lives of those affected with Spina Bifida through research, education and support, clinical care, network building, and advocacy.

UNITED CEREBRAL PALSY

<http://www.ucp.org>

Provides resources for individuals with cerebral palsy and other disabilities, their families, and their communities through an affiliate network.

UNITED SPINAL ASSOCIATION

<https://unitedspinal.org>

Supports people with spinal cord injuries and disorders (SCI/D) through valuable programs and services that maximize independence and create opportunities to become leaders, advocates, and innovators.

GOVERNMENT AGENCIES

ARCHITECTURAL ACCESS BOARD

<https://www.mass.gov/orgs/architectural-access-board>

Develops and enforces regulations designed to make public buildings accessible, functional, and safe for persons with disabilities.

BUREAU OF FAMILY HEALTH AND NUTRITION

<https://www.mass.gov/orgs/bureau-of-family-health-and-nutrition>

Provides programs and services ensuring the health of the Commonwealth's mothers, infants, children and youth — including children and youth with special health needs and their families.

DISABLED PERSONS PROTECTION COMMISSION

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

Phone: (617) 727-6465

(888) 822-0350 V/TTY

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

DIVISION FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH NEEDS

<https://www.mass.gov/orgs/division-for-children-youth-with-special-health-needs>

Promotes and supports good health and quality of life for children and youth with special health care needs and their families.

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 - MASSHEALTH

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

Information about the MassHealth program.

EXECUTIVE OFFICE OF HEALTH & HUMAN SERVICES - MASSHEALTH LONG-TERM CARE

<https://www.mass.gov/how-to/apply-for-masshealth-coverage-for-seniors-and-people-of-any-age-who-need-long-term-care-services>

Information about nursing facilities, residential care homes, assisted living facilities and other supervised living facilities for adults 65 years or older, or a person of any age in need of long-term-care services.

GOVERNOR'S COMMISSION ON INTELLECTUAL DISABILITY

<https://www.mass.gov/lists/governors-commission-on-intellectual-disability-gcid>

The Commission is an independent citizen oversight body consisting of 13 members appointed by the Governor for a term of three years. The Commission reviews public policy in the area of intellectual disability, and identifies and analyzes systemic areas of concern affecting the human service delivery system within Massachusetts.

MASS 211

<http://mass211.org>

Connects callers to information about critical health and human services available in their community. It serves as a resource for finding government benefits and services, nonprofit organizations, support groups, volunteer opportunities, donation programs, and other local resources.

MASSACHUSETTS ATTORNEY GENERAL'S OFFICE

<https://www.mass.gov/protecting-the-rights-of-people-with-disabilities>

Enforces Titles II and III of the Americans with Disabilities Act, the Massachusetts Public Accommodation Law, and the Massachusetts Equal Rights Act, and focuses on eliminating discriminatory barriers to services and ensuring accommodations for all people.

MASSACHUSETTS COMMISSION AGAINST DISCRIMINATION

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

Investigates and prosecutes Complaints of Discrimination that occur in Employment, Housing, Public Places, Access to Education, Lending, and Credit. Offers training to help prevent discrimination from occurring.

MASSACHUSETTS COMMISSION FOR THE BLIND

<https://www.mass.gov/orgs/massachusetts-commission-for-the-blind>

Serves individuals in Massachusetts who are legally blind by providing access to employment opportunities and social rehabilitation with the goal of increasing independence and self-determination.

MASSACHUSETTS COMMISSION FOR THE DEAF AND HARD OF HEARING

<https://www.mass.gov/orgs/massachusetts-commission-for-the-deaf-and-hard-of-hearing>

Provides accessible communication, education, and advocacy to consumers and private and public entities so that programs, services, and opportunities are fully accessible to persons who are deaf or hard of hearing.

MASSACHUSETTS DEPARTMENT OF DEVELOPMENTAL SERVICES

<https://www.mass.gov/orgs/department-of-developmental-services>

Provides supports for individuals with intellectual and developmental disabilities including Autism Spectrum Disorders.

MASSACHUSETTS DEPARTMENT OF EARLY EDUCATION AND CARE

<https://www.mass.gov/orgs/department-of-early-education-and-care>

Supports the healthy growth and development of all children by providing high quality programs and resources for families and communities.

MASSACHUSETTS DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION

<https://www.doe.mass.edu/>

The Department's work includes licensing educators, distributing state and federal education money, helping districts implement learning standards, overseeing statewide standardized tests, monitoring schools and districts, and convening districts and individuals to share best practices.

MASSACHUSETTS DEPARTMENT OF HOUSING AND COMMUNITY DEVELOPMENT

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

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

MASSACHUSETTS DEPARTMENT OF MENTAL HEALTH

<https://www.mass.gov/orgs/massachusetts-department-of-mental-health>

Provides access to services and supports to meet the mental health needs of individuals of all ages.

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

<https://www.mass.gov/info-details/dph-bureaus-and-programs>

Provides programs to address specific diseases and conditions, and offers services to address the needs of vulnerable populations.

MASSACHUSETTS DEPARTMENT OF TRANSITIONAL ASSISTANCE

<https://www.mass.gov/orgs/department-of-transitional-assistance>

Assists and empowers low-income individuals and families to meet their basic needs, improve their quality of life, and achieve long term economic self-sufficiency.

MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL

<https://www.mass.gov/orgs/massachusetts-developmental-disabilities-council>

An independent agency, funded by the federal government, dedicated to empowering people with developmental disabilities and their families to enjoy full productive lives by promoting self-sufficiency, community inclusion and opportunity.

MASSACHUSETTS EARLY INTERVENTION DIVISION

<https://www.mass.gov/orgs/early-intervention-division>

Program for infants and toddlers (birth to 3 years old) who have developmental delays or are at risk of a developmental delay.

MASSACHUSETTS OFFICE ON DISABILITY

<https://www.mass.gov/orgs/massachusetts-office-on-disability>

Serves as a resource to state agencies, municipalities, and members of the general public by providing information, guidance and training on matters concerning disability-related civil rights, equal access, and opportunity.

MASSACHUSETTS REHABILITATION COMMISSION

<https://www.mass.gov/orgs/massachusetts-rehabilitation-commission-0>

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. Since housing assistance is provided on behalf of the family or individual, participants are able to find their own housing, including single-family homes, townhouses and apartments

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>

Medicare is health insurance for people 65 or older. You may be eligible to get Medicare earlier if you have a disability, End-Stage Renal Disease (ESRD), or ALS (also called Lou Gehrig's disease).

SOCIAL SECURITY ADMINISTRATION

<https://www.ssa.gov>

Provides retirement, disability and survivor's benefits to eligible individuals.

UNIVERSAL ACCESS PROGRAM

<https://www.mass.gov/orgs/universal-access-program>

The Department of Conservation and Recreation's Universal Access Program provides outdoor recreation opportunities in Massachusetts state parks for visitors of all abilities.

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 in order to enhance the lives of people with special needs due to disability or age. The objective of both the national and Massachusetts chapters of NAELA is to promote the highest standards of technical expertise while maintaining ethical awareness among attorneys who represent the most frail and vulnerable members of society.

THANK YOU

A special thank you to all the contributors and proofreaders of this advocacy toolkit. Our anticipated ten-page toolkit has grown to a more than fifty-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.