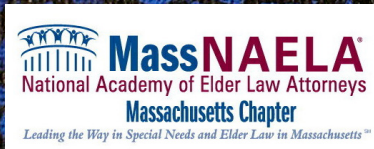




# SPECIAL NEEDS AND DISABILITY LAW TOOLKIT

THIRD EDITION



[www.MassNAELA.com](http://www.MassNAELA.com)

Michael Butler, *Up Up and Away*

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# PREFACE TO THE THIRD EDITION



Jason Melo, *Toucan*

It has only been three years since the release of the second edition of the toolkit and yet significant changes to laws affecting the lives of people living with disabilities in the United States warrants this update. Thanks to inspiring and empowered voices in the disability community, some long overdue changes to Supplemental Security Income (SSI) regulations have been made. In addition, the implementation of final rules of the Housing Opportunity Through Modernization Act of 2016 (HOTMA) clarifies and creates income and asset rules for federally subsidized housing programs, like Section 8. Distressing news this year from Florida alerts us to the ways in which pooled trusts, while an invaluable tool for the disabled community, require vetting and a “buyer beware” mentality and perhaps clear national policy and closer oversight. Finally, the rising prominence of supported decision-making nationwide brings Massachusetts legislation into focus.

These changes are briefly summarized in this preface, and further described in this third edition of the toolkit. 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.

## 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 of principal from special needs trusts (SNTs) will no longer be counted as income for Section 8 recipients. However, there is a new asset limit of \$100,000, which housing authorities will begin to implement in 2025.

## SOCIAL SECURITY

- *Omitting Food From In-kind Support and Maintenance Calculations.* Beginning September 30, 2024, the Social Security Administration (SSA) will no longer consider food expenses as a source of In-Kind Support and Maintenance (ISM).
- *Expansion of the Rental Subsidy Policy for Supplemental Security Income (SSI) Applicants and Recipients.* Beginning September 30, 2024, the SSA will no longer consider discounted rent as a source of In-kind Support and Maintenance (ISM), provided the SSI recipient pays monthly required rent equal to or exceeding the “Presumed Maximum Value” (PMV), or \$334 for 2024.

## RETIREMENT BENEFITS

- *SECURE 2.0* was passed in 2022. The first iteration of SECURE in 2020 created stricter distribution requirements for inherited retirement accounts. However, these rules exempted inherited retirement accounts left to qualifying supplemental needs trusts from these new stricter distribution requirements. SECURE 2.0 added additional protections for retirement accounts left to SNTs, including the ability to benefit charities after the death of the disabled trust beneficiary.

## SUPPORTED DECISION-MAKING

- *An Act Relative to Supported Decision-Making Agreements for Certain Adults with Disabilities – H1485 / S109 is currently pending in the Massachusetts legislature.* The proposed legislation would create a framework to create and enforce supported decision-making (SDM) agreements between people with disabilities and their trusted “supporters.” The proposed legislation would also require courts to consider SDM as an alternative to guardianship and/or conservatorship.

Further details regarding each of these updates is included in the corresponding chapters of this toolkit.

To those of you reading this toolkit in print format, please know you can also view the toolkit and short videos giving a brief overview to some of the sections at the following webpage:

<https://massnaela.com/specialneedstoolkit/>

Finally, this third edition of the toolkit has been greatly enhanced by the inclusion of original artwork by artists involved in Northeast Arc’s ArcWorks Community Art Center in Peabody, Massachusetts. For more information on the program please see the special thank you at the end of this toolkit.

# INTRODUCTION



Josh Lafauci, *Circular Pride*

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

A brief note regarding the language and terms used in this toolkit:

People in the disability community vary in the language they choose to use to describe themselves and others. Parents and supporters of people with disabilities (PWD) will often prefer the term “special needs” while a self-advocate may prefer to use “disabled person” and even be offended by the term “special needs.” In law, “special needs” is a term of art and why you will find it most often in this toolkit while discussing special needs planning, special needs trusts, and so forth. Nevertheless, this toolkit is for everybody whether they are a self-advocate PWD, a caregiver or friend, a supporter, a parent or family member, an ally, an appointed person such as a trustee or guardian, or a professional working in the disability community.

## 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 or a disability, 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.

## HOW TO BE A GREAT ADVOCATE

For most families and individuals living with a disability, 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 listed your goals, organized your team, and 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 with an issue in your child's group home, keep a journal and bring it with you to team meetings and medical appointments. If you write things down when they happen, it will carry more weight as a source of information.

## 7. SHARE THE ADVOCATE ROLE.

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

## 8. GET HELP WHEN CONFLICT ARISES.

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

## 9. MAKE YOUR MEETING PRODUCTIVE BY ORGANIZING YOUR RECORDS.


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

## 10. NURTURE RELATIONSHIPS.

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



# 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

# 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



Maryanne McCarthy, *Monet's Lily Garden*

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 families with infants and toddlers, birth to age three, who have, or are at risk for, developmental delays or disabilities. 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 a) is not meeting age-appropriate milestones; b) for whom there are developmental concerns due to an identified disability; or c) has a medical or social history which may put him or her at risk for developmental delay.

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,

tracheostomy 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 Mass. Family TIES website at <https://fcsn.org/family-ties>, or the Early Intervention website for the Massachusetts Department of Public Health at <https://www.mass.gov/info-details/about-massachusetts-early-intervention-ei>.

## Educational Entitlements (ages 3-22)

Students ages 3 to 22 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 (in Massachusetts, it is the Department of Elementary and Secondary Education). Massachusetts offers more rights for parents than the federal laws do. Massachusetts Special Education laws and regulations are found in 603 C.M.R. 28.00.

School districts are responsible for identifying and evaluating students suspected of having a disability 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 the student 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 substantially separate class or placement in a public or 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 (extended year services).

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

Schools must document a child's special education needs as well as the child's progress in school. Progress reports must be given every time report cards are distributed to a school's student body. Evaluations and other records can be helpful later in life to determine eligibility for adult services and other government benefit programs.

To connect with other parents and caregivers of special education students in your school district, contact your local SEPAC (Special Education Parent Advisory Council). Every school district is required to establish a SEPAC. 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.



Meghan Scire, *Picasso's Rooster*

## 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 a person is not capable of making his or her own decisions due to a disability, 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, putting a health care proxy in place means that the individual (known as the "principal") has thought through who he or she trusts to make medical decisions on his or her behalf, and is more likely to discuss his or her wishes with the chosen agent(s). Consequently, if the principal'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 principal and will have more knowledge of what he or she would have wanted. Second, if an individual over the age of 18 loses capacity to make medical decisions and has no health care proxy in place, a court process will be needed to appoint a guardian, and the guardian may not be a person who the individual would have chosen to be his or her medical decision-maker. In addition, the court process often leads to costs and delays that can be avoided if a health care proxy is in place.

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 and disabilities, 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.

Unlike a health care proxy, which is not activated unless or until the principal is determined to have lost the ability to make his or her own medical decisions, a HIPAA Authorization is in effect when signed. This means that the principal's trusted agent can access the principal's health information and speak to the principal's health care providers and help the principal make his or her own medical decisions if the principal wants and needs this help, even if the principal's health care proxy has not been activated.

## 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



Nick Gallant, *Big Blue Truck*

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 his or her own 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 and disability planning 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. In the event that the individual cannot sign a durable power of attorney, a court may need to appoint a conservator (see below).

Note all assets held in a joint account are viewed as belonging to either joint owner. Therefore, the individual must trust that the joint owner will use the assets for the individual's benefit. If the account is to hold significant funds, the individual may want to consider transferring the assets to a trust and naming a trustee to manage the funds for the individual. (See below, and also consult with an attorney about the right type of trust to consider.)

# 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 financial 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.

A representative payee is required to use the Social Security benefits for the disabled beneficiary's benefit. The representative payee must keep good records of how the benefits are spent, and SSA can ask the representative payee to provide an accounting to SSA at any time. In general, an individual representative payee cannot be paid for serving in the role. However, an organizational representative payee can be.

# Power of Attorney

A Durable Power of Attorney is a document that allows an individual (the "principal") to appoint an agent (also known as an "attorney-in-fact" or an "attorney") to make financial decisions on behalf of the principal. If a disabled individual has the capacity to sign legal documents, and has a trusted person in his or her life, he or she should sign a Durable Power of Attorney so that a trusted 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 investment account that an eligible individual can use to save funds for his or her disability-related expenses. What makes an ABLE Account unique is that it is an investment account, not a special needs trust, yet assets in the ABLE Account are non-countable for all federal public benefits programs, including SSI, Medicaid, and Section 8 housing. So an ABLE Account can be used by the disabled individual to accumulate and save more than program limits (for example, \$2,000 for SSI).

In addition, expenditures for Qualified Disability Expenses ("QDE") are not income for federal public benefits programs, and are income-tax free. (Other expenditures are partially taxable and subject to a 10% penalty.) QDEs are generously defined as any expense related to the designated beneficiary as a result of living with disabilities. QDEs 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. It even covers basic living expenses all people need, such as food and rent.

To be eligible, the individual must be blind or disabled before the individual's 26th birthday (or 46th birthday beginning in 2026, when the age limit will change). Documentation requirements may vary from ABLE program to ABLE program, but at a minimum the person establishing the ABLE Account must certify under penalties of perjury that the disability began prior to age 26 (age 46 in 2026 and beyond), and that the disabled individual



- is receiving SSI and/or SSDI benefits based on blindness or disability; or
- has a medically determinable physical or mental impairment that results in marked and severe functional limitations that can be expected to result in death or has lasted or is expected to last 12 months or more, and has obtained and will continue to retain a copy of the diagnosis relating to the disability signed by a physician.

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; but if the eligible individual cannot or does not designate one, then an attorney-in-fact, guardian or conservator, spouse, parent, sibling, grandparent, or Representative Payee designated by the Social Security Administration can open the account and become an authorized signatory. 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.

Like everything in life, there are limitations and tradeoffs. With some exceptions, annual contributions from all sources combined cannot exceed the federal gift tax exemption amount (\$18,000 in 2024, adjusted annually for inflation). Each state ABLE program has a maximum allowable balance, and amounts over \$100,000 are countable for SSI purposes. Finally, states that have paid Medicaid benefits for the Designated Beneficiary are permitted to recover those amounts at the Designated Beneficiary's death from the balance (if any) remaining in the ABLE Account.

Most state ABLE programs are open to residents of all states. The ABLE National Resource Center offers independent information about all state ABLE programs. To find out more, visit the website at [www.ablenrc.org](http://www.ablenrc.org).

## First-party Special Needs Trusts (SNTs)

A special needs trust ("SNT") funded with a disabled individual's own funds is called a First-party SNT (also known as a "(d)(4)(A) Trust," a "Payback Trust," or an "OBRA '93 Trust"). Similar to an ABLE Account, funds in a First-party SNT are non-countable for most (but not all) public benefits programs. But unlike an ABLE Account, where distributions for Qualified Disability Expenses (QDEs) are not counted as income, distributions from a First-party SNT to or for the benefit of the disabled beneficiary are treated, or not treated, as income in the same manner as all other receipts depending on the particular public benefits program in question.

Unlike an ABLE Account, there is no limit on the value of the assets in a First-party SNT, and no annual contribution limit. This makes a First-party SNT especially important in cases where the individual will receive a lump sum from a personal injury or divorce settlement, or an inheritance or gift.

However, all contributions to the First-party SNT must occur before the disabled beneficiary attains age 65. And all taxable income earned by the First-party SNT, whether or not distributions are made to or for the benefit of the disabled beneficiary, belongs to the disabled beneficiary for income-tax purposes; the trust itself does not pay income tax.

Like the ABLE Account, there is a tradeoff for all these benefits: the Medicaid payback. When the disabled individual passes away, any assets remaining in the trust must first be used to 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. This means there may be no assets left in the trust to pay out to remaining beneficiaries, such as siblings, children, or other family members.

But unlike an ABLE Account, where distributions for Qualified Disability Expenses (QDEs)+ are not counted as income, distributions from a first-party SNT to or for the benefit of the disabled beneficiary are treated, or not treated, as income in the same manner as all other receipts depending on the particular public benefits program.

A First-party SNT can be created by the disabled beneficiary with legal capacity (since December 13, 2016), or by that individual's parent, grandparent, or legal guardian, or by court order. Only a person with legal authority can transfer that individual's assets to the First-party SNT (the individual with legal capacity, an Agent under a valid Durable Power of Attorney with adequate powers, or a Conservator; a mere joint tenant on a bank account is insufficient).

Finally, unlike an ABLE Account, a First-party SNT is a trust. It is usually part of a comprehensive estate and special needs plan. You should seek competent legal counsel who focuses on special needs and disability law to advise on use and creation of the trust, and to provide counsel and guidance to the trustee. It is often helpful to name a professional trustee that understands the many legal aspects of SNT administration.

## Third-party Special Needs Trusts (SNTs)

Most parents want to leave assets to their children when they die. However, if a disabled individual receives assets outright while also receiving certain public benefits, the results can be disastrous. The person may lose SSI, public housing, and certain forms of state Medicaid programs.

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

In addition, if the trusted child dies before the disabled child, to whom do those assets pass? The trusted child's spouse? The trusted child's children? Perhaps without realizing it, the parent is depending on the trusted child to create and incorporate a Third-party SNT for the disabled sibling into their own estate planning. This is unreliable and unnecessarily complicates the trusted child's life. It is better for the parents themselves to establish a Third-party SNT.

Unlike a first-party SNT, a Third-party SNT is funded with money and assets of anyone except the disabled individual (most commonly, the inheritance the parents leave for their disabled child). Unlike a First-party SNT, the age of the disabled individual does not matter. Like a First-party SNT, a Third-party SNT is non-countable for most public benefits programs, and can protect trust assets from having to be "spent down" while, at the same time, making the assets available to enrich the life of the person with a disability without jeopardizing benefits available from the government.

A Third-party SNT can be funded with anything: cash and investments, real estate, life insurance, estate assets distributed through one's Will, or tax-deferred retirement plans such as IRAs and 401(k)s. It should not, however, own an asset that is a potentially serious liability waiting to happen, like a motor vehicle.

Despite the term "special needs," a well-drafted Third-party SNT is not limited to extraordinary or special expenses. Rather, it can be used to pay for anything - any goods or services - for the disabled beneficiary. (In most states, so can a First-party SNT.) Like a First-party SNT, distributions may impact public benefits, depending on the program, but that does not mean a Third-party SNT must prohibit such distributions.

Unlike a First-party SNT, there is no Medicaid payback in a Third-party SNT. At the death of the beneficiary, any remaining trust property can be distributed to other family members or even to a charity.

## SPECIAL NOTE: TAX-DEFERRED RETIREMENT PLANS

Beginning in 2020, tax-deferred retirement plans such as Traditional and Roth IRAs, 401(k)s, and 403(b)s must pay out all funds to death beneficiaries within ten years of the original owner's death. The primary exception is if the death beneficiary is the surviving spouse, who can withdraw funds over her life expectancy or "roll over" the retirement plan so that the surviving spouse is deemed the original owner.

Fortunately, another exception to the "all out in ten-years" rule is for Third-party SNTs for the sole lifetime benefit of a disabled or chronically-ill individual. If such a Third-party SNT is named as death beneficiary of the retirement plan, or the retirement plan owner's revocable trust is named which on death (in whole or in part) funds such a Third-party SNT, the trustee may withdraw funds from the retirement plan over the life expectancy of the disabled beneficiary. This enables the trustee to have much greater control year to year over the use of trust funds and the income-tax consequences of making a withdrawal. In addition, the ability to stretch the distributions over the lifetime of the disabled beneficiary allows the retirement plan to continue to grow while deferring income tax until such time as a withdrawal is made. In the case of a Roth plan, the plan gets to compound over the beneficiary's life expectancy and withdrawals are income-tax free.

In contrast, retirement plans can be problematic when a parent wishes to leave an inheritance for non-disabled children in trust for asset-protection purposes. Traditional (non-Roth) retirement plan withdrawals are income-taxable events. Undistributed trust taxable income is taxed at the top federal rate (37% - 2024) at extremely low amounts of annual income (\$15,200 – 2024). If distributed, it is taxed to the beneficiary at individual rates, but now asset-protection is lost.

## Pooled Special Needs Trusts

For many individuals and families, identifying a knowledgeable and responsible Trustee to manage a SNT can be a major hurdle. Some issues that families face are the lack of available trusted family members to serve as Trustee, the complexity and demands of being a SNT Trustee, or the minimum asset values required by many professional trustees, trust companies and banks before they will agree to serve as Trustee for an individual trust. Pooled special needs trusts can offer a solution.

Unlike a stand-alone SNT, a pooled SNT combines (i.e., pools) the funds of disabled beneficiaries to maximize investment returns and lower the costs of trust administration. Each disabled beneficiary who contributes funds to the pooled trust is allocated a sub-account to ensure that each beneficiary's funds and investment returns are separately accounted for and tracked.

Instead of an individual serving as Trustee, the pooled trust is managed by a nonprofit organization, which serves as Trustee. The organization is comprised of professionals, including social workers, attorneys, and advocates, who are well-versed and up-to-date on issues affecting the lives of disabled beneficiaries, especially the need to preserve eligibility for government benefit programs while also enhancing the lives of their beneficiaries. The nonprofit organizational Trustee often partners with financial experts to maximize investment returns.

As with stand-alone SNTs, pooled SNTs are available as First-party or Third-party trusts. Like a stand-alone First-party (d)(4)(A) trust, a First-party (d)(4)(C) pooled trust must include a Medicaid pay-back provision. In Massachusetts, the beneficiary may be 65 or older when the (d)(4)(C) trust is funded. However, a Third-party pooled trust - like a stand-alone Third-party SNT - does not require a payback provision, and can be established for any disabled beneficiary, regardless of the beneficiary's age.

While pooled trusts offer a valuable option to families and individuals looking for an alternative to identifying an individual Trustee, and/or lacking the necessary funds to pay for a professional Trustee, pooled trusts are not all the same. Each pooled trust will have its own joinder agreement, fees, rules,

staff, and board of directors, and even its own goals. Before choosing a particular pooled trust, it is advisable to vet and compare options, much like a consumer would do before choosing a financial advisor, professional trustee, attorney, or other professional.

Recent news provides a cautionary tale. In March 2024, the Tampa, Florida-based Center for Special Needs Trust Administration (“The Center”) filed for bankruptcy in U.S. Bankruptcy Court. The Center accused its founder, Leo Govoni, of having fraudulently “borrowed” \$100 million from the trust fund between 2009 and 2020. Reportedly, more than 1,500 trusts are missing money, with almost 900 trusts left with balances of less than \$500. Most of the Center’s beneficiaries were disabled persons, whose trusts were funded with the proceeds of personal injury settlements. It remains unclear how these beneficiaries will be compensated for their loss.

A very similar case was initiated in 2022 and is still ongoing against Synergy Settlement Services, Inc. In both cases, a key issue was that the nonprofit trustee engaged in business transactions with related for-profit entities (investment advising and wealth management, settlement services, etc.), meaning the owners and managers/board of directors were the same or similar, thereby creating wealth for the owners and board members while potentially being harmful or being disloyal to their beneficiaries. (Please note that these cases are still being investigated and adjudicated.)

These examples are not meant to scare families and individuals away from using a pooled trust in their planning. Rather it serves as a warning for us that we must always be vigilant in our plans and in our team of supporters. Vetting a pooled trust (or financial advisor, or corporate trustee, etc.) requires more than asking about fees. To make an informed decision, additional information is needed, such as:

- Does the pooled trust have fiduciary liability insurance for intentional bad acts and unintentional misdeeds? Note that Board of Directors and Officers (B&O) insurance coverage is not sufficient, since it is not intended to make beneficiaries whole.
- Does the pooled trust have a system of checks and balances in Master Agreements and operations?
- Does the pooled trust engage in independent audits?
- Does the pooled trust engage independent investment advisors and wealth managers?
- Does the pooled trust offer an internet portal for beneficiaries to see their accounts in real time? How many written statements or accountings are provided to the beneficiary each year?

## Conservatorship

If an individual with special needs does not have the capacity to sign a Durable Power of Attorney, or does not have a trusted person to name as an agent in the Durable Power of Attorney, or, due to unique circumstances, requires court oversight, then as a last resort a conservatorship may be required. However, it is preferable to utilize the other options discussed above because the legal costs and ongoing court oversight required in a conservatorship can be expensive and time-consuming.

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 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. Note that in Massachusetts, a court does not need to find a person is legally incapacitated to order conservatorship (as opposed to a guardianship), only that the person needs additional support to manage his or her finances due to potential risk to the individual’s income or assets.

# MEDICAL INSURANCE



Michael Butler, *In The Desert*

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. 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 may also be covered, as well as 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). However, it is possible these plans may choose to be generous in coverage regardless.

The Autism Insurance Resource Center can tell you if your company has to comply with ARICA, and the staff may be willing to advocate for coverage with your company (774-455-4056, <https://massairc.org/>).

## **COVERAGE FOR MENTAL HEALTH SERVICES**

Under the Massachusetts 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**

Under Federal 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 Health 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.

However, when it comes to MassHealth benefits provided to people who need long-term services and supports (LTSS), the level of care, and the eligibility rules, are different. 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 also 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- and out-patient hospital treatment;
- lab tests and 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 and PT) • Intermediate care (ICF/MR) • In-patient psychiatric care for individuals under the age of 21 and 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, the state is required to provide coverage for medically necessary treatment.

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

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

## **MEDICAID-FUNDED HOME AND COMMUNITY-BASED WAIVER PROGRAMS**

Many states offer Medicaid-funded waiver programs that provide 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, a children's autism waiver, and a frail elder waiver for adults who are 60 or older.

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 individuals 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 main 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.

In recent years, there has been a rise in the number of dual eligible disabled adults and children. They are eligible for both Medicaid and Medicare in Massachusetts. It is optional to maintain these programs under separate management, or sign up for a D-SNP plan. Dual Eligible Special Needs Plans (D-SNPs) enroll individuals who are entitled to both Medicare (title XVIII) and medical assistance from a state plan under Medicaid (title XIX). The Commonwealth of Massachusetts may cover some Medicare costs, depending on the individual's eligibility.

These plans are similar to Medicare Advantage plans for seniors in that they offer basic medical services and a host of additional services and supports not traditionally covered by Medicare, such as transportation, care coordination and more. It is important to review the provider list and service options of each D-SNP plan to make sure it is a good fit for your needs, or you may even opt out of the plan.

## **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



Meghan Scire, *Old Fogies*

## 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 to 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 individual needs and capabilities along with the strengths and needs of the individual's caregivers. The MASSCAP consists of the following three parts.

The ICAP (Inventory of Client and Agency Planning) is a tool that assesses the individual's adaptive functioning and the level of support and supervision that the person needs. The areas assessed by ICAP are Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. The ICAP scores range from zero to three points. Zero points 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.

The CCA (Consumer and Caregiver Assessment) is a tool that assesses the resources and supports that are currently in place for the individual and provides information to assist in evaluating the capacities of the caregivers. The CCA looks at the current caregiver and his or her ability to continue to provide support in a manner that keeps the individual safe from harm.

Finally, the information provided by the ICAP and the CCA, as well as the direct observation of the individual and interviews with family members, is reviewed by 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 the Department to determine whether an individual has an assessed need for a requested service. In certain circumstances, the Department may request supplemental functional or targeted assessments in order to provide additional information in making the determination of an individual's need for supports.

Once MASSCAP has been completed and the individual is found to have a need for service, the next step in the process is to determine the prioritization level for that service within existing resources of the Department. Prioritization is an administrative tool that separates needs into three groups: Priority 1, Priority 2 and No Priority.

Priority 1 means that provision, purchase or arrangement of supports available through the Department is necessary to protect the health or safety of the individual or others. Under Priority 1 needs, the service planning should be initiated and services should be arranged or provided within 90 days.

Priority 2 means that provision, purchase or arrangement of supports available through the Department is necessary to meet one or more of the individual's needs or to achieve one or more of the needs identified in his or her Individual Service Plan. Under Priority 2 needs, the Department should be engaged in active planning with the family or individual within 90 days, and services should be provided or arranged within 12-18 months. This time period, however, is dependent on funding.

A No Priority determination means that services are not considered a priority for funding by DDS.

## SUPPORTS INTENSITY SCALE

The Supports Intensity Scale (SIS), which has been developed by the American Association on Intellectual and Developmental Disabilities (AAIDD), is utilized by the Department in assessing the support needs of individuals found eligible for DDS adult services as persons with 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. (However the law does not cover MassHealth Day Habilitation programs. A bill to expand Nicky's Law to cover MH Day Habilitation programs is pending at the time of the this toolkit's publication.)

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 days of receipt of a Request for DMH Services application, DMH will contact the applicant or guardian to acknowledge receipt of the application. Within 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 (“two-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 two-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 clinical criteria, that denial 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 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,” within 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 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 Reconsideration.

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

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 14 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](https://fcsn.org/transition_guide/english.pdf)

# FEDERAL PROGRAMS THAT PAY CASH BENEFITS



Arelis O'Neal, *Lighthouse*

## 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 \$1,550/month if the income is from work (\$2,590/month for a person who is blind), and no more than \$963 if the income is not from work, such as unemployment benefits or pension payments;
- not own more than \$2,000 in assets in his or her own name;
- be a United States citizen or national, or non-citizen in certain classifications granted by the Department of Homeland Security; and
- not be confined to an institution at government expense

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 2024 is \$943/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, among others:

- cash;
- 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:

- the home lived in and the land it is located on;
- most personal belongings and household goods;
- one automobile of any value if used for transportation;
- medical equipment such as a wheelchair;
- UTMA account for someone who is under the age when termination of the account is required;
- 529 education plan, if the person seeking SSI benefits is the beneficiary of the plan but not the owner;
- small life insurance policies;
- burial spaces and small burial funds;
- property needed for self-support;
- property properly set aside under a Plan to Achieve Self Support (PASS);
- 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 \$1,550/month in 2024 (\$2,590/mo in 2024 for individuals who are blind). 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 \$65 of earned income and 50% of earnings over \$65. 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 \$2,220 per month to a maximum of \$8,950 per year (as of 2024).

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, but is not limited to, Social Security benefits, pension payments, and unemployment benefits.

Some types of unearned income, such as food stamps, home energy assistance, disaster assistance and income tax refunds, will not be counted.

In-kind Income. A person's SSI benefits will be reduced if he or she receives "in-kind support and maintenance" (ISM), which is shelter the person receives and does not pay the full value to acquire. Due to a recent regulatory change, food has been removed from the calculation of ISM. Another regulatory change, as of September 30, 2024, concerns the calculation of ISM for SSI recipients who pay discounted rent. If an adult SSI recipient lives in the home of another and does not pay for the full cost of rent, his or her monthly benefit will be reduced unless the recipient is paying rent that is equal to or greater than \$334 per month, (that is, one-third of the maximum SSI rate (\$314), plus \$20, which is known as the Presumed Maximum Value (PMV)), if the SSI applicant is paying at least \$334 in rent, in which case there will be no reduction to his or her SSI benefit.

## 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 2024, a person earns one credit for each \$1,730.00 earned per quarter in wages or self-employment income; a person must have worked 40 quarters, not just ‘earned’ 40 x \$1,730). 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). To receive benefits, a child must have a parent who is retired or has a disability and is entitled to Social Security benefits, or a parent who died after having worked long enough in a job where they paid Social Security taxes.

If a child of a worker who meets these requirements 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 \$1,550/month (as of 2024) in competitive employment (\$2,590 if blind), or maybe 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 (Note that if the child worked, and 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 render the child ineligible); 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 \$1,550/month as of 2024).

### **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, 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



Meghan Scire, *Three Goats*

## Where Adults with Disabilities Live and Who Pays for It

There are no entitlements to residential services in Massachusetts for those over the age of 22. However, there are numerous kinds of residential arrangements and more become available each 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 or caregiver (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, 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, although the Massachusetts Rehabilitation Commission (MRC) and Massachusetts Commission for the Blind (MCB) also have a limited amount of funds. Money flows through these state agencies to contracted “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 and not diagnosed with ID are not eligible to 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 federally-funded Tenant Based Voucher program, also known as Section 8. (“HUD” refers to the federal Department of Housing and Urban Development.) 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 a 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 five to ten 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 two-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 two 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/>

## HOTMA CHANGES

In 2023, HUD issued final regulations implementing parts of the Housing Opportunity Through Modernization Act of 2016 (HOTMA) affecting Section 8. Although effective January 1, 2024, LHAs have until July 1, 2025 to implement these changes. Important changes include:

- There is now a limit on “net family assets” of \$100,000 (adjusted annually for inflation).
- Previously Section 8 had no asset limit *per se*, but countable assets still mattered on account of imputed income (see below).
- Among assets excluded from counting toward the \$100,000 are up to \$50,000 of non-necessary tangible personal property, retirement plans, 529 Plans, and ABLE Accounts.
- Income is now imputed on net family assets in excess of \$50,000 (adjusted annually for inflation), up from \$5,000 previously. (Income matters because typically the Section 8 recipient's out-of-pocket rent is 30% of income, and there is an income limit for public housing that varies by geographic area.)

HOTMA has also brought some order and clarity to treatment of trusts of which the Section 8 recipient is a beneficiary. Revocable trusts, and irrevocable trusts under the control of a member of the household, are countable assets, and income earned by the trust is countable income whether distributed or not. In contrast, irrevocable trusts **not** under the control of a family member are not countable assets, and only distributions of income (but not of principal) is income to the individual.

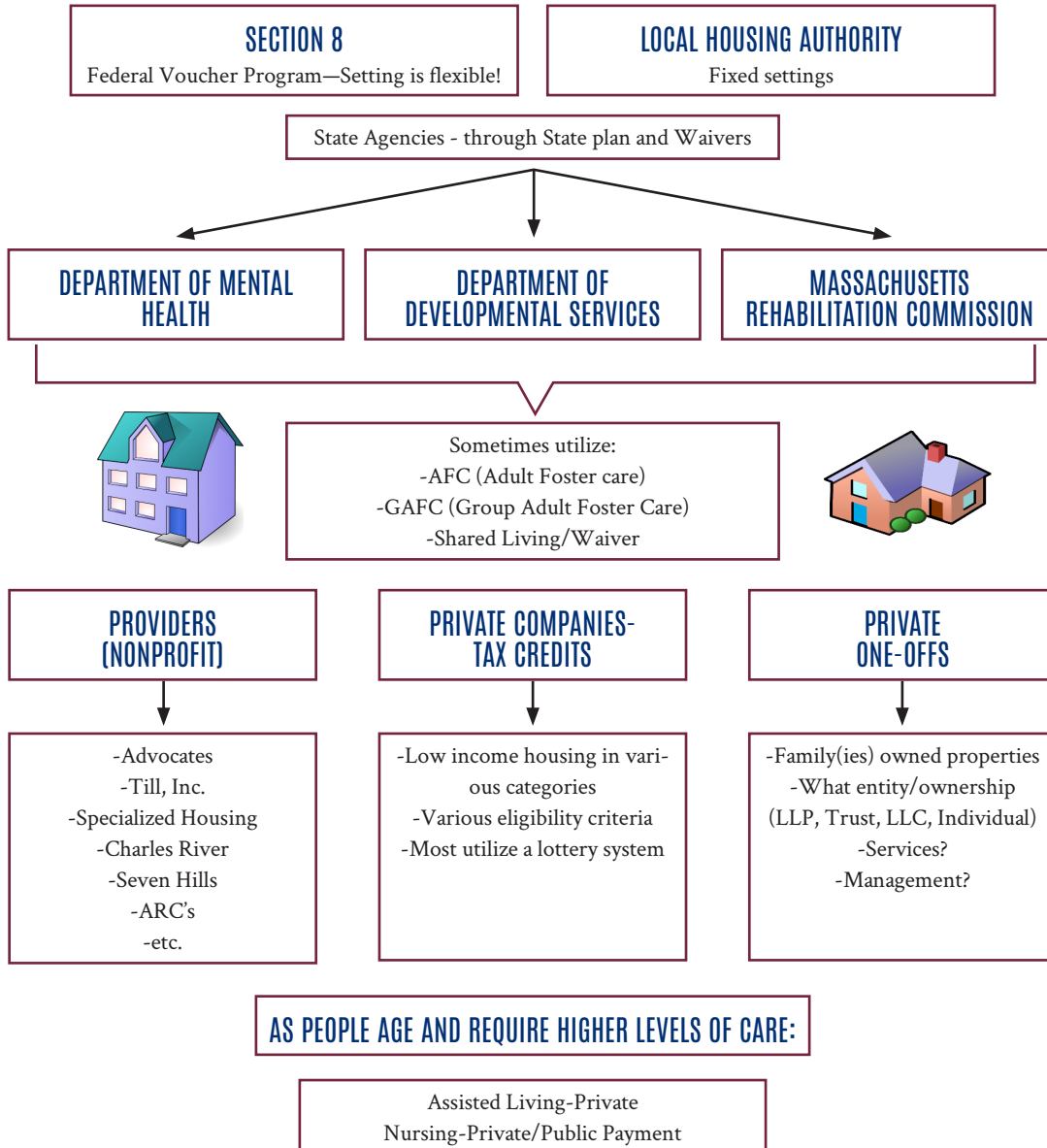
If you are unsure whether your assets or income are countable under these final regulations, please seek assistance from a qualified special needs attorney or community support organization.

## RECENT LEGISLATION

Governor Maura Healey recently signed an affordable housing act that includes supports for people with disabilities. This legislation is critical to tackle the affordable housing crisis we have in Massachusetts and particularly in our disability community. Most notably are zoning reforms for “accessory dwelling units” or ADUs which are beyond the scope of this toolkit but which provide some much needed relief to people with disabilities and their families when seeking affordable housing options.



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





# RESOURCES

Greg Marcheterre, *Big Yellow*

## 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.

## **INSURANCE RESOURCE CENTER FOR AUTISM AND BEHAVIORAL HEALTH**

<https://massairc.org/>

Resources for consumers, providers, clinicians, employers, and educators on issues related to medical insurance for autism and behavioral treatments.

## **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

This edition of the toolkit has been greatly enhanced by the inclusion of original artwork by artists involved in Northeast Arc's ArcWorks Community Art Center in Peabody, Massachusetts. Northeast Arc was founded in 1954 by parents of children with disabilities who wanted to raise their sons and daughters as full members of the community. Today Northeast Arc positively impacts the lives of approximately 10,000 people in nearly 190 cities and towns across Massachusetts. The goal of the Northeast Arc is to ensure that children and adults with disabilities or autism are able to live, work, engage in civic life, and play in the community. Artists and entrepreneurs are supported to explore, experience, and create work through a variety of mediums. Artists are connected to the creative economy to exhibit and sell their works. Learn more at <https://ne-arc.org/>.

Special thanks to Susan Dodge, ArcWorks's Program Director, who was instrumental in providing access to the original art featured in this edition of the toolkit.

Finally, heartfelt thanks 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 and disability 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.