



# TALKING THE TALK

## TERMS AND ACRONYMS FREQUENTLY USED IN THE DISABILITY COMMUNITY

### Frequently Used Terms

#### **ABLE Account (also 529A account, 529A plan):**

A type of savings plan made available through the Achieving a Better Life Experience Act of 2014 which, like a 529 college savings plan, provides professionally managed, tax-advantaged investment portfolios designed to help families save for the future care of a child with disabilities. <https://www.ablenrc.org/>.  
<https://nast.org/able-advocacy/>.

#### **Adult Family Care (AFC):**

A program for adults with disabilities and frail elderly adults who cannot live alone safely. Trained, paid caregivers, who may be friends or family but not a spouse or guardian, will live with the AFC eligible adult and provide care in a home setting. <https://adultfamilycare.org/>

## **Advocate:**

A person who will work to ensure the rights of a person with disabilities are met and not violated. They may be granted specific powers, such as access to rehabilitation and school records, as well as the authority to release records, to approve placement or services, to attend meetings, and to advocate generally on behalf of the individual with a disability. They may be a paid advocate or a family member or friend who has the best interest of the individual at heart.

## **Conservator (also guardian of the estate):**

A person appointed by the court and given authority to handle the financial affairs of a person who is unable to manage finances on their own. A conservator does not make any personal decisions for the individual and is not responsible for providing for the individual from their own financial resources.

## **Crummey provision:**

A trust provision allowing the trust beneficiary to withdraw a specified amount of funds during a limited time each year. It is often used in a life insurance trust to qualify the amount that can be withdrawn as a present interest for the annual gift exclusion amount.

## **Entitlement benefits:**

Benefits provided by government agencies that a person has the legal right to receive if certain requirements are met. Examples include Medicare, Medicaid, Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI), among others.

## **Estate:**

All assets a person possesses at the time of their death, including securities, real estate, interests in businesses, physical possessions, death benefit of life insurance policies, and cash. There will be an estate tax imposed by a state or the federal government when assets left to heirs exceed a specified level of exclusion.

## **Fiduciary:**

A person, company, or association who is responsible for investing the assets of a beneficiary in a prudent manner. For example, a trustee is a fiduciary.

## **Guardian (also Guardian of the person):**

A person appointed by the probate court to assume decision-making responsibilities for an individual who is unable to make decisions for themselves. The person requiring the guardian is legally called a ward, or more commonly known as a protected person, or incapacitated person.

The guardian has the legal authority and responsibility to oversee the physical and medical care of the protected person and their property. When a child reaches age 18 a parent must apply for guardianship, if appropriate, to be able to make decisions on behalf of the adult child. To read more: [10 FAQs about Guardianship.](#)

## **Individual Service Plan (ISP):**

The ISP provides the written details of the supports, activities, and resources required for the individual to achieve personal goals. It is developed to articulate decisions and agreements made during the person-centered planning process. An ISP meeting needs to take place within three months of an individual turning age 22.

## **Individualized Education Plan (IEP):**

The IEP is a legally binding document outlining a plan for a child, who has a disability identified under the law, to receive specific services in school. It is intended to help the child reach educational goals more easily than they otherwise would and to help teachers and related service providers understand the student's disability and how the disability affects the learning process. An IEP is meant to ensure that students receive an appropriate placement and specialized assistance, not "only" special education classrooms or special schools and interact with and participate in the activities of their more general school peers.

## **Legal documents:**

There are documents, including wills, trusts, powers of attorney or advocate and health care proxies that need to be legally formalized. In addition, there are some roles that need to be legally appointed including guardian, conservator, and personal representative. Legal documents need to be created with a knowledgeable disability law attorney in the resident's state.

## **Letter of Intent (LOI):**

Although not legally binding, this document communicates your desires and concerns to future caregivers. It covers vital statistics, your child's financial picture, details about what works well or not so well for your child, suggestions about what changes might be needed for the future, a list of the locations of all pertinent documents and records, and individuals that are important in your child's life. Read more and download a [fillable Letter of Intent](#).

## Life Care Plan:

A comprehensive document that determines the future costs required to support an individual who has become or is disabled. This is commonly used in a legal settlement or in developing a person-centered plan.

## Life Insurance:

Life insurance is an important part of planning for the future. In general, life insurance will provide a cash payment to stated beneficiaries after the death of the person who is insured by the policy. Most parents of a child with special needs should have some type of life insurance in place; preferably a permanent policy that provides for lifelong protection.

### Types of Life insurance:

#### ***Permanent life insurance:***

A policy designed to provide lifelong financial protection; if the necessary premiums are paid, the death benefit will be paid. Most permanent policies have a feature known as cash value that increases (tax deferred) over the life of the policy and can be used to help fund financial goals or future premiums.

#### ***Survivorship life insurance:***

A policy that insures two individuals and pays the death benefit at the death of the second insured. The premiums are significantly less than two separate insurance policies because the policy insures two lives for one benefit.

#### ***Term life insurance:***

A policy covering the insured for a certain period of time, or term. The policy pays death benefits only if the insured dies during the term, which can be 1, 5, 10, 20 or even 30 years.

#### ***Universal life insurance:***

A type of permanent life insurance that allows the policy holder, after their initial payment, to pay premiums at any time, in virtually any amount, subject to certain minimums and maximums. This policy also permits a reduction or increase in the death benefit more easily than a traditional whole life policy. Also called adjustable life insurance.

#### ***Whole life insurance (also ordinary life insurance):***

A type of permanent life insurance. With this type of policy, premiums generally remain constant over the life of the policy and must be paid periodically in the amount specified in the policy. Also accumulates cash value as universal life.

### ***Long-term care insurance (LTCI):***

Insurance coverage that, under specified conditions, provides money to help pay for skilled nursing care, home health care, or personal or adult day care for individuals with a chronic or disabling condition and who need constant supervision. LTCI offers more flexibility and options than many public assistance programs; however, one must qualify for coverage based on certain health provisions prior to purchasing a policy.

### ***Long-term disability (LTD) insurance:***

LTD coverage is intended to protect your income if you are unable to work due to illness or injury. It does not pay for the cost of care like LTCI does. Qualification is based on certain provisions of underwriting, including health status and income earnings. While short-term disability insurance usually lasts a maximum of two years, long-term coverage can often last five or 10 years, and may last through to your retirement.

## **Massachusetts State Agencies:**

### ***Massachusetts Department of Developmental Services (DDS):***

DDS manages and oversees a comprehensive system of specialized services and supports for individuals with intellectual disabilities and children with developmental disabilities. These supports include day supports, employment supports, residential supports, family supports, respite and transportation. <https://www.mass.gov/orgs/departments-of-developmental-services> .

### ***Massachusetts Commission for the Blind (MCB):***

MCB is a state agency providing a wide range of social and rehabilitation services to the legally blind residents of all ages. <https://www.mass.gov/orgs/massachusetts-commission-for-the-blind>

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

MCDHH provides accessible communication, education and advocacy to consumers and entities to make programs, services, and opportunities fully available to people who are deaf or hard of hearing. <https://www.mass.gov/orgs/massachusetts-commission-for-the-deaf-and-hard-of-hearing>

### ***Massachusetts Department of Mental Health (DMH):***

DMH is an agency providing public mental health services and overseeing an integrated system of state and provider operated adult and child mental health services.

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

### ***Massachusetts Rehabilitation Commission (MRC):***

MRC is responsible for rehabilitation and community services and eligibility determination for the SSDI and SSI federal benefits program. <http://www.mass.gov/eohhs/gov/departments/mrc/>

## **Medicaid:**

A joint federal and state program that helps with medical costs for people with low incomes and limited resources. Medicaid programs vary from state to state, but most health care costs are covered if an individual qualifies for both Medicare and Medicaid. People with Medicaid may get coverage for things such as nursing home care and outpatient prescription drugs that are not covered by Medicare.

## **Medicare:**

The federal health insurance program for people 65 years of age or older, and for certain younger people with disabilities.

## **Personal Care Assistant (PCA):**

A MassHealth Program that helps people with long-term disabilities live independently at home. Gives eligible member funds to hire a PCA to help with activities of daily living.

## **Person Centered Planning (PCP):**

PCP is a process-oriented approach to empowering individuals with disabilities. It focuses on the development of a "toolbox" of methods and resources that enable the person with disabilities, their caregivers and loved ones to choose their pathways to success. The role of the planners is to help them determine where they want to go and how best to get there.

## **Personal representative of the estate:**

The individuals or corporations who are appointed in a will who have the legal responsibility for carrying out the provisions of the will to the best of their ability, according to the current federal and state laws. The personal representative(s) may seek the assistance of an attorney to complete the process of settling an estate. This role used to be referred to as the executor.

## **Power of Attorney (POA) (also Durable Power of Attorney, Durable Power of Attorney for property):**

A legal document that authorizes someone else to handle certain matters, such as managing finances, buying and selling property, filing tax returns, or applying for government benefits. At the time the person is creating the POA, they appoint a person as their agent, or attorney-in-fact, to act on their behalf when/ if they are unable to act on their own behalf. If the power is durable, it remains in effect if the person becomes incapacitated due to illness or accident.

### **Power of attorney for health care (also Health care proxy):**

A legal document granting decision-making powers related to health care to an agent; generally provides for removal of a physician, the right to have the incompetent patient discharged against medical advice, the right to medical records, and the right to have the patient moved or to engage other treatment. If the power is durable, it remains in effect if you become incapacitated due to illness or accident.

### **Protected person (also ward, incapacitated person):**

A term for a person under guardianship or conservatorship.

### **Representative payee:**

When an individual is not capable of managing their own Social Security benefits (including SSI, Railroad Retirement, Veterans benefits), a person or agency may be named to manage the funds received from these benefits. This representative payee will have authority only over the proceeds of checks where they are designated as payee and must provide detailed records of the distribution of these funds. A person having power of attorney over an individual does not automatically qualify that person to be a representative payee.

### **Section 8 housing assistance:**

The Section 8 Housing Choice Voucher Program is the federal government's major program for assisting very low-income families, the elderly, and individuals with disabilities to rent decent, safe, and sanitary housing in the private market. Because housing assistance is provided on behalf of the family or individual, participants can find and rent privately owned housing, including single-family homes, townhouses, and apartments. The participant is free to choose any housing that meets the requirements of the program and is not limited to units located in subsidized housing projects.

### **Social Security Disability Insurance (SSDI):**

A program financed with Social Security taxes paid by workers, employers, and self-employed persons. To be eligible for an SSDI benefit, the worker must earn sufficient credits based on taxable work. Disability benefits are payable to workers with disabilities, disabled widows or widowers, or adults disabled since childhood who are otherwise eligible. Auxiliary benefits may be payable to a worker's dependents as well. The monthly disability benefit payment is based on the SSDI earnings record of the insured worker on whose Social Security number the disability claim is filed. <https://www.ssa.gov/benefits/disability/>

## Supplemental Security Income (SSI):

The SSI program provides monthly income to people who are blind or disabled and who have limited income and financial resources. The individual's financial resources (savings and assets owned) cannot exceed \$2,000 (\$3,000 if married). If only one person of a married couple is eligible, a portion of the spouse's income may be counted. Individuals can be eligible for SSI even if they have never worked in employment that is covered under Social Security. <https://www.ssa.gov/ssi/>

## Supported decision making (SDM):

An alternative to guardianship that allows an individual with a disability to make choices and decisions about their life with the support of a designated person or team of trusted supporters.

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

## Trust:

A legal arrangement under which an individual (grantor) gives fiduciary control of property to a person or institution (trustee) for the benefit of a beneficiary.

## Trust advisor:

An individual, often a family member or friend, who will provide input on behalf of the beneficiary to the trustee. This role does not carry fiduciary responsibility but allows involvement in the activity of the trust.

## Trustee:

The individual or individuals who manage a trust. They have a fiduciary responsibility for seeing that trust funds are properly invested and disbursed according to the wishes of the individual who created the trust.

## Special needs trust (SNT) (also supplemental needs trust):

A type of trust that is commonly used for a person with disabilities for the purpose of supplementing any government benefits that the individual would be eligible to receive, while protecting their eligibility for certain Medicaid programs and services, SSI, and other public benefit programs that have an asset or income limit. The SNT can be a first-party, third-party, or pooled trust.

### Types of Special needs trusts:

#### ***First-party special needs trust (also payback, self-settled, (d)(4)(A) trust under OBRA '93):***

This type of trust allows an individual with disabilities to deposit their own assets into the trust, while also being the trust's sole beneficiary and protecting their eligibility for certain government benefits. Upon the death of the beneficiary, any remaining assets in the trust would first be subject to pay back Medicaid for expenses made on their behalf.



### ***Special needs pooled trust (SNPT):***

A type of trust permitted by Medicaid and federal law that pools the resources of many beneficiaries with disabilities; the resources are managed by a non-profit association or charity. Unlike individual disability trusts, which may be created only for people under age 65, Pooled trusts may be for beneficiaries of any age, and may also be created by the beneficiary. In addition, at the beneficiary's death, the state does not have to be repaid for its Medicaid expenses on the beneficiary's behalf if a portion of the funds are retained by the charity.

### ***Third-party special needs trust:***

This is the most common trust used in special needs planning; often established by a parent, grandparent, or someone other than the beneficiary. Any assets, other than those owned by the beneficiary, may be deposited into this type of SNT without jeopardizing the eligibility, current or future, of certain government benefits that have an asset limit. The funds are to be used to supplement what the beneficiary receives from government benefits. Upon the death of the beneficiary, the remainder assets will be distributed to whoever is named in the trust documents as the successor or remainder beneficiary. The key is that this trust is funded with other people's money, not money from the beneficiary, and there is no payback to Medicaid upon the death of the beneficiary. These trusts are commonly testamentary trusts, funded upon the death of a parent or grandparent, often using proceeds from life insurance.

### ***Ward (also protected person, incapacitated person):***

The legal term for a person under guardianship or conservatorship.

## Frequently Used Acronyms

<b>ABLE</b>	Achieving a Better Life Experience or 529A account
<b>ADA</b>	Americans with Disabilities Act
<b>ADL</b>	Activities of Daily Living
<b>AFC</b>	Adult Family Care
<b>ASD</b>	Autism Spectrum Disorder
<b>BTP</b>	Bureau of Transitional Planning
<b>CFP®</b>	Certified Financial Planner Professional
<b>ChSNC®</b>	Chartered Special Needs Consultant
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>DD</b>	Developmental Disability
<b>DMH</b>	Department of Mental Health
<b>DDS</b>	Department of Developmental Services
<b>DESE</b>	Department of Elementary and Secondary Education
<b>DPH</b>	Department of Public Health
<b>DPPC</b>	Disabled Person's Protection Commission
<b>DCF</b>	Department of Children and Families
<b>EOHHS</b>	Executive Office of Health and Human Services
<b>HIPAA</b>	Health Insurance Portability and Accountability Act of 1996
<b>ID</b>	Intellectual Disabilities
<b>IDEA</b>	Individuals with Disabilities Education Act
<b>IEP</b>	Individual Education Plan
<b>ISP</b>	Individual Support Plan
<b>ITP</b>	Individual Transition Plan
<b>LEA</b>	Local Education Authority
<b>LOI</b>	Letter of Intent
<b>LTCI</b>	Long-term Care Insurance
<b>LTD</b>	Long-term Disability Insurance
<b>MASSCAP</b>	Massachusetts Comprehensive Assessment Process
<b>MASHEALTH</b>	Massachusetts Office of Medicaid, MassHealth
<b>MCB</b>	Massachusetts Commission for the Blind
<b>MCCD</b>	Massachusetts Coalition for Citizens with Disabilities
<b>MCDDH</b>	Massachusetts Commission for the Deaf and Hard of Hearing

<b>MDDC</b>	Massachusetts Developmental Disabilities Council
<b>MRC</b>	Massachusetts Rehabilitation Commission
<b>PASARR</b>	Pre-Admission Screening and Annual Resident Review
<b>PCA</b>	Personal Care Assistant
<b>PCP</b>	Person Centered Planning
<b>POA</b>	Power of Attorney
<b>SDM</b>	Supported Decision Making
<b>SNPT</b>	Special Needs Pooled Trust
<b>SNT</b>	Special Needs Trust
<b>SPED</b>	Special Education
<b>SSA</b>	Social Security Administration
<b>SSDI</b>	Supplemental Security Disability Income
<b>SSI</b>	Supplemental Security Income

Sources: Massachusetts Department of Developmental Services, DDS Transition Information, Special Needs Planning Guide, Haddad/Nadworny, SibTips, Haddad/Nadworny

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