SPECIAL NEEDS ALLIANCE

# WHAT YOU NEED TO KNOW ABOUT BEING AN ADULT WITH DISABILITIES

A handbook for self-advocates, parents, guardians, and their loved ones.

2026

# Table of Contents

# 1. Introduction and Definition of Terms

## Introduction

Supportive services and legal arrangements are only part of a person's transition to adulthood. Relationships, education, employment, and housing options involve additional perspectives and resources that require complex coordination and a full picture understanding of the individual's unique needs. Legal services should be combined with available resources to promote independence and maximize available resources to sustain such independence. Often, when the parents are the attorney's clients, it is easy to advocate for the most protective arrangements that grant the parents maximum control (e.g., guardianship) over the disabled individual. However, in utilizing the tools available a balance can be achieved with maintaining autonomy and appropriate safeguards in place. For parents of disabled children aged 16, 17, or 18 years old, legal and social services professionals (like vocational rehabilitation) can assist him/her in achieving an appropriate balance.

This handbook will provide the caregiver, parent, or service provider with the necessary information needed to understand (1) the terms related to services and supports for individuals with disabilities, (2) the process of transitioning from child services to adult services, and (3) the options and resources available to individuals with disabilities.

Many laws affecting individuals with disabilities are state specific, including statutes regarding powers of attorney and guardianship; thus, it is critical that the caregiver or parent receive legal advice in their specific state. It is best not to assume that the laws affecting our community apply equally. In some instances, this document will refer to uniform laws prepared by the Uniform Law Commission. These uniform laws *may* be adopted by various states, often with additional state-specific amendments. In other cases, some states will have their specific laws which have not been adopted uniformly.

## Legal Definitions

1. **Disability**: According to the federal Americans with Disabilities Act (ADA), a person with a disability is defined as "an individual having physical or mental impairment that substantially limits one or more major life activities."

2. **Incapacity**: A lack of physical, mental, or cognitive ability that results in a person's inability to manage their own personal care, property, or finances; a lack of ability to understand one's actions when making a will or other legal document.

3. **Testamentary Capacity**: The mental or cognitive ability to understand and execute estate planning documents such as a will, trust, or power of attorney. In most states this is a low standard, and even a person who is subject to guardianship or conservatorship may have testamentary capacity. The requirements of testamentary capacity can vary from state to state, but generally testamentary capacity means the person must understand the following:

    a. What they are doing (i.e., that the power of attorney allows someone else to make decisions for them, or that a will tells who the person would like to get their assets when they die);

    b. Who they are appointing (i.e., be able to express why they want a certain person to be the decision maker);

    c. What they are directing (that someone else gets to make decisions for them or that specific people will get their assets when they die); and,

    d. What they are giving (the authority to make decisions or identify the assets they will be devising in their will).

4. **Agent**: The person who is authorized by another person (the principal or health care proxy) to deal with third parties and has the power to make decisions or take actions on behalf of the principal.

5. **Principal**: The main person who directs another person to act on their behalf or delegates their own decision-making to another person.

6. **Rights of Survivorship**: A feature of one type of joint ownership between two or more owners of an asset, such as a bank account or land. When the first owner dies, the remaining owner(s) then own the decedent's portion without taking any legal action.

    - For example, if John and Mary own a house as joint tenants with rights of survivorship and John dies, Mary becomes the sole owner. She doesn't need a court ruling or another deed to establish her ownership.

7. **Public Benefits**: Public benefits are forms of assistance from the government, usually for individuals and families with limited resources and income.

8. **Medicaid**: A joint federal and state program that helps cover medical costs for individuals with limited income and resources.

9. **Medicare**: The federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD).

10. **Supplemental Security Income (SSI)**: A federal program funded by U.S. Treasury general funds. The U.S. Social Security Administration (SSA) administers the program, but SSI is not paid for by Social Security taxes. SSI provides cash payments to disabled adults without a sufficient work history and for children who have limited income and resources. Household income can limit the receipt of SSI.

11. **Social Security Disability Insurance (SSDI)**: A federal government program that pays a cash benefit to individuals who have a sufficient work history prior to becoming disabled or are a dependent or survivor of a disabled, retired, or deceased insured worker deemed disabled by SSA prior to the age of 22. There is no resource limit for SSDI eligibility. Recipients of SSDI will also qualify for Medicare benefits after two years regardless of their age.

12. **Intellectual/Developmental Disability Waiver**: Often referred to as the "I/DD Waiver," this is a Medicaid program that provides services to individuals with a qualifying intellectual or

developmental disability. These services can include housing, care giving, day services, supported employment and therapies. Because the I/DD Waiver program is jointly funded by the federal and state governments, the services provided will differ from state to state.

13. **Guardian ad Litem**: Also referred to as a "GAL," an attorney appointed by the court to evaluate a specific case only, and to report their findings and recommendations to the court. The evaluation, report, and recommendations are based upon the best interests of the protected person.

14. **Protective Arrangements**:

    - **Guardianship**: The legal role, granted as a result of a court process, to manage the personal decisions or resources of another person who cannot properly do so on their own. A child may need a legal guardian in situations where a parent is not available. An adult may need a guardian (also called a conservator of the property or estate in some states) when a court determines they have a disability that prevents them from exercising good judgment or if the person acts overly reckless or harmful to their welfare. Rights such as medical decisions, the right to marry and where a person resides may be transferred to the guardian.
    - **Conservatorship**: The legal role, granted as a part of a court process, to manage the financial affairs of a person who is unable to handle them due to their incapacity. Some states use the term "guardian of the property or estate" for a court-appointed party to manage someone's financial matters.
    - **Adult Protective Services**: The legal process initiated to support vulnerable adults experiencing abuse, neglect, or exploitation. Adult Protective Services is a state-run program with the core mission of investigating reports of harm, abandonment, exploitation, neglect and connect vulnerable adults with safety and support services. APS can coordinate emergency shelter, transportation, food, home repairs or safety modifications, medical or mental health services, and assistance in managing money.
    - **Power of Attorney**: A document that gives legal authorization for a designated person to make decisions about another person's property, finances, or medical care. The requirements for these documents will vary from state to state.
    - **Surrogate Healthcare Decision Maker**: A decision maker for a patient who is unable to make decisions for themselves and has no legally authorized representative.

# 2. Decision-Making Options

There may be times when an individual with disabilities needs help making decisions about finances, healthcare, housing, and other life choices. Therefore, it is important to understand the various decision-making options that range from support from others to full guardianship.

## Supported Decision Making Agreement - Least Restrictive Alternative to Guardianship

Supported decision making agreement is a legal contract between an individual with a disability and a trusted "supporter." A Supported Decision-Making Agreement is a **written document** in which an adult voluntarily designates one or more "supporters" to assist him/her with understanding information, weighing options, and communicating decisions. The adult **retains full legal authority** over all decisions. The agreements are designed to preserve a disabled adult's **autonomy**, **civil rights**, and **decision-making authority**, while allowing them to choose trusted supporters to help them understand, consider, and communicate decisions. Supported Decision Making Agreements are widely recognized across the country – some states have enacted legislation that not only recognizes the agreements but also acknowledges certain penalties for supporters who breach their duties to the disabled individual.

A supported decision-making agreement includes:

**(a) Voluntariness & Capacity Requirements**: An adult may enter an SDMA only if: (1) he/she does so **voluntarily**, without coercion or undue influence and (2) he/she **understands the nature and effect** of the agreement.

**(b) The Adult Retains All Rights**: Executing an SDMA **cannot be used as evidence of incapacity** and the adult may still act independently, even if an SDMA exists.

**(c) Supporters**: A supporter must be identified in the document, be at least **18 years old**, and must voluntarily agree to serve as a supporter.

**(d) Scope of Supporter Authority**: Supporters may help with understanding information, communicating decisions, accessing records (if authorized in the agreement) and implementing decisions. Supporters **cannot** make decisions for the adult or override the adult's choices.

**(e) Revocation & Modification**: The adult may **change or revoke** the agreement at any time.

**(f) No Mandatory Use**: No third party may require an SDMA as a condition of service or access.

**(g) Collaboration with Other Documents**: If the adult has a SDMA and also has a Durable Power of Attorney and/or Advanced Health Care Directive, these documents can work together and not against one another. Used together, these documents create a layered, least-restrictive framework that various courts increasingly anticipate before considering guardianship or conservatorship.

## Powers of Attorney (Uniform Power of Attorney Act)

• Requirements for the Power of Attorney (POA) to be valid:

(a) The principal must have mental capacity to understand what they are signing (this means that the individual understands the nature of the POA, the powers that are; being granted, and the identity of the named agents) – a medical exam is not required;

(b) It must be in writing;

(c) It must be signed by the principal (electronic signatures are not recognized in many states); and,

(d) It must be notarized and may also need to be witnessed depending on state law;

(e) The named agent must be a competent adult and someone whom the principal trusts.

• Durable Power of Attorney:

A **Power of Attorney (POA)** and a **Durable Power of Attorney (DPOA)** look similar on paper, but they behave very differently once the principal becomes incapacitated. The distinction is legally significant in probate, Medicaid, and conservatorship work. It is important to remember that a POA is **not durable** unless it explicitly says otherwise. A non durable POA becomes **void** if the principal becomes incapacitated and, as a result, the agent's authority ends the moment the principal loses capacity.

A POA becomes **durable** only if it contains language showing the principal intends the authority to continue after incapacity.

Typical language: "This power of attorney shall not be affected by the subsequent incapacity of the principal."

Once that language is present, the agent's authority continues even if the principal later becomes unable to make decisions.

## Duties, Responsibilities, and Limitations of a Financial POA

A financial POA describes the agent's authority to make decisions regarding the principal's assets. This can include accessing bank accounts, paying bills and taxes, selling or transferring real property, managing a business, and managing investment accounts. The POA may contain a general grant of authority which may imply certain authority under state law. However, some authority must be express.

The POA must contain language specifically outlining the authority delegated to the agent. Without express language granting authority to do so, the agent typically CANNOT do any of the following:

- Create or change beneficiaries;
- Alter rights of survivorship;
- Give gifts;
- Make changes to an inter vivos (living) trust;
- Create and fund an irrevocable trust;
- Further delegate the authority created by the POA;
- Control the principal's electronic communications; or
- Waive certain entitlements for the principal.

An agent owes the principal certain mandatory duties. These include:

- Acting in accordance with the principal's reasonable expectations to the extent actually known by the agent and, otherwise, in the principal's best interest;
- Acting in good faith; and
- Acting only within the scope of authority granted in the POA.

Except as otherwise provided in the POA, an agent that has accepted their appointment shall:

- Act loyally for the principal's benefit;
- Act without creating a conflict of interest that impairs the agent's ability to act impartially in the principal's best interest;
- Act with care, competence, and diligence ordinarily exercised by agents in similar circumstances;
- Keep a record of all receipts, disbursements, and transactions made on behalf of the principal;
- Cooperate with a person that has the authority to make healthcare decisions for the principal to carry out the principal's reasonable expectations to the extent actually known by the agent and otherwise act in the principal's best interest; and
- Attempt to preserve the principal's estate plan, to the extent actually known by the agent, if preserving the plan is consistent with the principal's best interest based on all relevant factors, including:
    - The value and nature of the principal's property;
    - The principal's foreseeable obligations and need for maintenance;
    - Minimization of income, estate, inheritance, generation-skipping transfer and gift taxes; and,
    - Eligibility for a benefit, a program, or assistance under a statute or regulation.

## Advanced Health Care Directive

An **Advance Health Care Directive** is a written legal document that lets an adult decide in advance what medical care he/she wants—and who can make decisions for him/her—if they later become unable to speak for themselves. It is the core planning document for medical autonomy.

The document addresses **medical treatment preferences** (life sustaining treatment, pain management, mental health care, end of life decisions), **appoints a health care proxy/agent** (someone who can make medical decisions if the person becomes incapacitated), and it provides **instructions to providers** that must follow the directive unless legally prohibited.

An individual who has mental health diagnosis can add specific provisions to the document which allows him/her to express preferences about psychiatric care, crisis intervention, and treatment limitations. This is an important document for a disabled individual as it allows him/her to state preferences regarding medications, hospitalization, treatment plans, crisis stabilization, and who may make decisions if they cannot.

You can draft provisions addressing:

- Preferred psychiatric medications
- Medications the person refuses (e.g., antipsychotics with prior adverse reactions)
- Consent or refusal for electroconvulsive therapy (ECT)
- Preferences for inpatient vs. outpatient treatment
- Preferred hospitals or crisis centers
- Triggers, de-escalation strategies, and crisis plans
- Instructions for law enforcement interaction
- Authorization for supporters to communicate with providers
- Preferences on sensory issues and how he/she wishes to be "handled"
- Wishes regarding anatomical donations.

## Surrogate Healthcare Decision Makers

- Some states, with significant variation across the country, have laws that provide a process and priority for the designation of surrogate healthcare decision makers.
- In the absence of a designated healthcare agent for an incapacitated person, a surrogate healthcare decision maker may be appointed to uphold the best interest of the patient. For that surrogate to be designated, pursuant to the Uniform Healthcare Decisions Act, two qualified healthcare professionals must determine that the patient lacks capacity to make their own healthcare decisions. One of these professionals shall be the patient's primary care physician.
- For individuals with developmental disabilities, the second professional shall be a person whose training and expertise aid in the assessment of functional impairment (physician, physician assistant, social worker, psychologist, nurse). In the event an individual is assessed to lack capacity to make healthcare decisions, a surrogate healthcare decision maker may be required if there is no agent (i.e., no POA) or court-appointed guardian in place, or if the agent or guardian is not reasonably available.
- The Uniform Health Care Decisions Act contains specific provisions identifying who may or may not serve as a surrogate. At any time, an individual for whom a surrogate is designated may challenge the determination of the need for a surrogate or the designation of a specific person to act as surrogate, by a signed writing or by telling their healthcare provider (i.e., their doctor) that they do not agree with the designation of a healthcare surrogate. A challenge regarding an individual's capacity will prevail unless otherwise ordered by court proceedings.

The role of a surrogate healthcare decision maker is generally intended:

- To be short term;
- To address a current medical issue; and,
- To avoid any long-term oversight.

Therefore, it is suggested that guardianship be sought for someone whose lack of capacity is clinically determined to be long-term or permanent.

Generally, surrogate decision-making laws authorize surrogates to make decisions regarding:

- The selection and discharge of healthcare providers and institutions;
- Approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate;
- Directions relating to life-sustaining treatment, including withholding or withdrawing life-sustaining treatment, and termination of life support; and,
- Directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of healthcare.

## Guardianship (as it pertains to incapacitated adults, not to minor children)

Legal guardianship of an adult is one of the most intrusive legal interventions a court can impose. It removes some or all of an adult's civil rights and transfers decision making authority to another person. The **Uniform Guardianship and Protective Proceedings Act** requires **clear and convincing evidence** that the adult cannot meet essential needs even with appropriate supports.

Legal guardianship is a court ordered arrangement in which a judge appoints a guardian to make personal decisions for an adult who is found to be unable to make or communicate informed decisions about their own care. It typically covers: medical decisions, residential placement, daily living decisions, and safety and personal welfare. The adult becomes a **"ward"** and loses the right to make decisions in the areas the court transfers to the guardian.

A court may appoint a guardian only if:

1. The adult is **incapacitated**—meaning they cannot receive, evaluate, or communicate information to meet essential health and safety needs; **and**
2. The adult's needs **cannot be met by less restrictive alternatives**, such as:
    - Supported Decision-Making Agreements
    - Powers of Attorney
    - Advance Directives
    - Representative payees
    - Community supports

Many courts will require the court appointed guardians to submit regular written reports regarding any changes to the ward's condition, living conditions, or other substantial changes. A guardian can be a family member, friend, or an independent third party. In many states, before a court will rule that a person is incapacitated in the context of a guardianship proceeding, there must be sufficient evidence to support the underlying medical cause of the alleged lack of capacity (e.g., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse). This may come in the form of medical records, a doctor's report or sworn testimony.

## Conservatorship/Guardian of the Estate

Typically, conservatorship is a protective arrangement ordered by a court granting a third party the legal authority to make financial decisions for an individual who has been determined to lack capacity to make financial decisions in their own best interests.

A conservatorship is a court ordered protective arrangement in which a judge appoints a conservator to manage an adult's financial affairs and property because the adult is found unable to do so safely or effectively. It requires clear and convincing evidence and is permitted only when **no less restrictive alternative** can protect the adult's financial interests. It is the financial counterpart to guardianship (which covers personal and medical decisions).

A conservatorship may be imposed only if the petitioner proves, by clear and convincing evidence, that:

1. The adult is **unable to manage property or business affairs, and**
2. The adult's property will be **wasted, dissipated**, or **not used for their support** without court intervention, **and**
3. **No less restrictive alternative** (DPOA, representative payee, SDMA, trusts, joint accounts, bill pay services, etc.) can meet the adult's needs.

A conservatorship may remove the adult's ability to:

- Manage bank accounts
- Pay bills
- Enter contracts
- Control income or assets
- Sell or buy property
- Handle legal or financial transactions

The conservator becomes a **fiduciary** with authority over the adult's finances, subject to court oversight.

- Conservators often make decisions similar to those that a financial power of attorney would make, such as dealing with bank accounts, bill paying, real property, business decisions, investments, and taxes.
- Conservators are typically monitored by the court through regular written reports or hearings and often are required to be bonded.
- A conservator can be a family member, friend, or an independent third party.
- In many states, before a person can be found incapacitated by the court in the context of a conservatorship proceeding, there must be sufficient evidence to support the underlying medical cause of the alleged lack of capacity (e.g., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse). This often means the individual will be evaluated by a psychologist or psychiatrist to determine his/her capacity.
- In many states, the alleged incapacitated person may also be represented in a conservatorship proceeding by a Guardian ad Litem or by an attorney of their choosing, or as appointed by the court.
- Some states use the term "guardian of the property or estate" for a party appointed by the court to manage someone's financial matters.

## Comparison Chart: Adult Decision Making Tools

| Feature | Guardianship | Conservatorship | DPOA and AHCD | Supported Decision Making Agreement (SDMA) |
|---|---|---|---|---|
| **What it covers** | Personal decisions: medical care, residence, daily needs | Financial/property decisions | Financial, legal, and sometimes personal decisions (if included) | Any decisions the adult chooses to receive support with |
| **Who has authority** | Court appointed guardian | Court appointed conservator | Agent chosen by the adult | Adult retains full authority; supporters assist only |
| **Effect on adult's rights** | Removes rights in areas granted to guardian | Removes rights to manage finances | Adult retains rights; agent acts as representative | No rights removed; adult remains the decision maker |
| **Requires court order** | Yes | Yes | No | No |
| **Standard required** | Clear & convincing evidence of incapacity + no less restrictive alternative | Same standard as guardianship | Capacity to contract | Capacity to understand the agreement |
| **Court oversight** | Ongoing reporting and monitoring | Ongoing accounting and monitoring | None | None |
| **When it takes effect** | Upon court order | Upon court order | Immediately or upon incapacity (depending on document) | Immediately |
| **Can it avoid guardianship?** | No | No | Yes—strong evidence of least restrictive alternatives | Yes—explicitly recognized as a least restrictive alternative |
| **Revocability** | Only by court | Only by court | Revocable by adult if they have capacity | Revocable by adult at any time |
| **Who chooses the decision maker** | Court | Court | Adult | Adult |
| **Use cases** | Severe cognitive impairment; inability to meet essential needs | Inability to manage money or property safely | Planning tool for autonomy; avoids conservatorship and avoids guardianship | Autonomy-preserving support for adults with disabilities or mental health needs |
| **Impact on litigation** | Last resort; must prove no alternatives work | Same | Strong evidence adult can manage with supports | Very strong evidence of least restrictive alternatives |

# 3. Benefits and Services

## Medicaid Waivers

Medicaid benefits are administered by each state pursuant to federal and state laws and regulations and are funded with a combination of federal and state resources. Some states request exceptions to federal rules (called “waivers”) to allow flexibility in the design of programs and use of federal funds. This allows each state to make its own decisions about eligibility and services provided under the waiver. Medicaid waiver programs are usually administered through a state’s department of health, department of human services, or a similar agency.

To apply for the waiver program, an application must be filed with the state agency that administers the program. Supporting documentation is typically required, including medical records to prove the disability and financial records to prove financial eligibility.

- Intellectual/Developmental Disability Waiver (I/DD Waiver);
- May be part of the Home and Community Based Waivers Services system;
- Usually under the state’s Medicaid umbrella so benefits may be dramatically different from state to state;
- Usually provides supports to individuals with a qualifying intellectual or developmental disability.

- Supports may include:
    1. Physical therapy;
    2. Occupational therapy;
    3. Speech therapy;
    4. Assistive technology;
    5. Home modifications;
    6. Home healthcare;
    7. Case management services;
    8. Respite services;
    9. Supported living; family living; independent living;
    10. Community supports services sometimes known as “day hab”); and
    11. Supported employment services.
        - The I/DD Waiver may also provide necessary items such as incontinence supplies, oxygen, feeding supplies;
        - The I/DD Waiver is typically not a cash program;
        - Those eligible for the I/DD Waiver usually will also receive Medicaid as their health insurance program to cover the costs of doctor’s visits, hospitalizations, and medications;
        - Many states have waiting lists of months or years for the funding and allocation of services; and
        - Eligibility is typically based upon the Social Security definition of “disability” along with a financial eligibility requirement.

## Social Security: SSI and SSDI

SSI and SSDI are two federal disability programs administered by the Social Security Administration. Both provide monthly income to individuals who cannot work due to disability, but they have different rules, different benefits, and different eligibility requirements.

If an individual is under the age of 18, the income of the entire household (i.e., the parents or guardians) is counted toward determining financial eligibility through a concept called “deeming.” Once an individual is 18 years of age only his/her income is counted toward determining financial eligibility – even if the adult still resides at “home” with his/her parents.

Applications for these benefits are submitted through the Social Security Administration’s website found at www.ssa.gov. Documentation to prove the disability and financial eligibility is required.

### Supplemental Security Income (SSI)

SSI is a cash benefit program for individuals who have no or very low income and very limited resources. Every eligible individual receives the same amount of money each month regardless of the nature of the qualifying disability, the level of their needs, or the state in which they reside. Eligibility for SSI requires that the individual:

- Be over age 65; or blind or disabled;
- Have limited income and resources (generally under $2,000 for an individual);
- Be a U.S. citizen or national, or in one of certain categories of aliens;
- Reside in of one of the 50 states, the District of Columbia, or the Northern Mariana Islands; and
- Not be confined to an institution (such as a hospital or prison) at the government’s expense.

It is important to remember that with SSI you do not need a work history to qualify. It is designed to provide funds to individuals to meet their basic living expenses. In many states, when you are approved for SSI, you automatically qualify for Medicaid.

## What does "disabled" mean for SSA purposes?

For those under age 18, there must be a medically determinable physical or mental impairment, (including an emotional or learning problem) that:

- Results in marked and severe functional limitations; and
- Can be expected to result in death; or
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

For those over age 18, there must be a medically determinable physical or mental impairment (including an emotional or learning problem) that:

- Results in the inability to engage in substantial gainful activity; and
- Can be expected to result in death; or
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

## What is considered "income"?

- Earnings from paid employment;
- Money received from other sources, such as Social Security benefits, workers compensation, unemployment benefits, veterans' benefits, gifts or bequests from friends, or relatives; and
- Free shelter.

## What is considered a "resource"?

- Cash;
- Bank accounts;
- Stocks, mutual funds, and U.S. savings bonds;
- Land (real property not used as a primary residence);
- Extra vehicles (one vehicle is exempt);
- Personal property of value;
- Life insurance; and
- Anything else that the applicant owns that could be converted to cash and used to pay for their shelter expenses.

**There are two exceptions to the $2,000 rule:**

- Up to $100,000 held in an ABLE account is not counted and
- Funds in a special needs trust.

These two exceptions are discussed in more detail below.

## Social Security Disability Income (SSDI)

The SSDI program pays cash benefits to the disabled wage earner (WE) and certain family members if the WE is "insured." This means that the WE worked enough "quarters" and paid Social Security taxes on their earnings. This equates to roughly 5 out of the last 10 years. The cash benefit amount is based upon the number of "work credits" the worker has earned prior to becoming disabled. Eligibility for SSDI requires that the worker worked and paid into Social Security; and has a medical condition that meets Social Security's definition of disability.

There is no resource limit for receiving SSDI.

It is important to know that once you are approved for SSDI, after 24 months, the recipient will automatically receive Medicare.

| **Feature** | **SSI** | **SSDI** |
|---|---|---|
| Based on financial need | Yes | No |
| Based on work history | No | Yes |
| Resource limit | Yes | No |
| Health insurance | Medicaid (immediate in some states) | Medicare (after 24 months) |
| Benefit amount | Fixed, income based | Based on past earnings |
| Can you get both? | Sometimes | Sometimes |

## Childhood Disability Benefit

Another type of SSDI benefit is called the Childhood Disability Benefit. An adult who has a disability that began before age 22 may be eligible for this benefit if their parent is deceased or starts receiving retirement or disability benefits. Social Security considers this a "child's" benefit because it is paid on a parent's Social Security earnings record.

For any type of Social Security benefit, a Representative Payee may be appointed to manage the benefits if the Social Security Administration has determined that the beneficiary is not able to do so themselves. See Section 6 below for more information about Representative Payees.

## Vocational Rehabilitation ("Vocational Rehab" or "VR")

Vocational Rehabilitation (VR) is a program that helps individuals with disabilities prepare for, obtain, keep, or return to employment. It is designed to support individuals with physical, mental, cognitive, or developmental disabilities. The goal is to help individuals achieve competitive, integrated employment that matches their abilities and interests.

VR is usually administered by the state government and may be a part of the state's education department, human services department employment division, or social services department. Individuals begin receiving services while enrolled in public school and referrals occur as early as 14 years of age.

### Who is Eligible?

An individual who has a physical, mental, emotional, or learning disability that is a barrier to the individual getting and keeping a job, including services to prepare the individual to get, keep, or regain employment.

### Is VR Required for Everyone with a Disability?

Before a VR agency can determine that an individual cannot benefit from VR services, it must explore the individual's work potential through a variety of assessments and trial work experiences. Trial work experience might include supported employment or on-the-job training in realistic work situations. The trial work experiences must:

- Be in competitive, integrated employment settings to the maximum extent appropriate;
- Be of sufficient variety and over a sufficient length of time to determine whether the individual can benefit from services; and,
- Provide needed support (such as assistive technology and personal assistance services).

### VR for Students

Additional school-to-work transition services called "Pre-Employment Transition Services" (Pre-ETS) are provided by VR agencies to students with disabilities while they are still in secondary school. Pre-ETS do not require VR eligibility determination.

### VR services are individualized and may include:

- **Career counseling and job placement**
- **Training or education** (college, trade school, certifications)
- **Job coaching and supported employment**
- **Assistive technology** (hearing aids, communication devices, adaptive equipment)
- **Workplace accommodations**
- **Transportation assistance and/or training**
- **Resume and interview preparation**
- **Assistance in maintaining employment**
- **Benefits counseling** (how work affects SSI/SSDI)

For individuals with significant disabilities, VR can provide **long-term supported employment** and job coaching.

## Care Management for the Child with Special Needs, Whether a Minor or an Adult

Ensuring proper in-home support is critical. This includes the following:

- Support personnel that is properly trained for the child's needs so that parents have the personal and physical assistance they need to maintain full-time care;
- Ensuring that all eligible waivers are applied for to facilitate funding for support; and,
- Access to additional activities, such as day programs, classes, and other available resources.

It's important to create a transition plan for the adult child who lives at home but will need a new arrangement after the child's parents are no longer able to provide the necessary care, due to their own disability or death.

- If the hope is that the child moves in with another family member, is that plan feasible? Who will pay for it? How will the move happen logistically? Who will provide care in the interim until the move can occur?
- If a group home or assisted living facility is necessary, how will it be paid for? Have parents or guardians toured and selected a facility? Is the child on the correct waitlists in the appropriate state?
- What support does the child need – emotionally, mentally, and physically – while the plan is being implemented?
- In what state is all this happening? If the child is moving to a new state, what benefits will be maintained, what will need to be applied for, and how long is the transition or waiting period in between?

Also, see Section 5, below/Living Arrangements.

# 4. Transitions for School and Work

## Extended Education/School Year ("ESY")

### What is ESY?

Extended school year (ESY) services are special education and related services that are provided to a student with a disability beyond the regular school year in accordance with the student's Individualized Education Program (IEP). The need for ESY services must be determined annually on an individual basis by the student's IEP team.

### Who is eligible?

Eligibility for ESY services is assessed by a student's IEP team. An existing IEP for the student - or special education services provided in school do not automatically make the child eligible for ESY. Eligibility varies by school district and/or state and must be determined by the student's IEP team annually. Parents can request an ESY program through the student's school district or at the next IEP meeting. Similar to other decisions made by the school district, if a student is denied ESY services, the parent can appeal.

The two most common factors reviewed for determining eligibility for ESY are regression and recoupment. Is the child at risk of regressing – losing skills and knowledge – during a break from school? The IEP team will also look at recoupment – how long it might take for the child to regain the skills and knowledge they may have lost during the academic break. If a summer break or school vacation is likely to lead to a significant regression in the progress the child has been making, and/or if the student's progress will be significantly delayed when the academic break is over, the school will determine what services may be required to prevent that from happening.

Other factors may include:

- If the student is close to a breakthrough in learning;
- If progress has stalled toward a specific IEP goal; and,
- If the student needs to continue learning a critical skill related to self-sufficiency and independence.

## Supported Employment

### What is Supported Employment?

Supported employment refers to services for obtaining and maintaining employment for people with disabilities, including intellectual disabilities, mental health, and traumatic brain injury, among others. Supported employment is one form of paid employment, in which wages are expected, including additional worker benefits from the employer in a competitive workplace setting, though some versions involve disability agency-paid employment.

### What are the key features of a Supported Employment Program?

- Provides training and on-site competence support to the individual with disabilities until they learn the job.
- Facilitates job opportunities for the individual.
- Targets jobs that an individual with disabilities may not otherwise have knowledge of or know how to access.

### What else is important to know?

- A supported employee may be the only employee with a disability in the work setting.
- A supported employment setting cannot have more than six employees using supported employment services.
- A supported employee can be self-employed in their own business.

### How does it work?

A vocational rehabilitation counselor works with the individual to formulate a plan for supported employment. As part of the planning process, the individual can select a community-based service provider from those available in the community. Services provided by the selected community-based service provider included a vocational evaluation, job development, and job coaching. Funding begins with the vocational rehabilitation program and then is continued by the state developmental disability agency at a time designated in the supported employment plan.

## Day Habilitation

### What is Day Habilitation?

Day Habilitation is a service that supports individuals with intellectual and developmental disabilities who need help acquiring, retaining, or improving socialization and adaptive skills to improve their community experience, as well as the experience of other members of the community. Day habilitation participants learn new skills and achieve greater independence.

# 5. Living Arrangements

Finding suitable housing and living arrangements for an individual with disabilities is often a high priority for the individual and their family. Yet, finding an appropriate and affordable arrangement can be a significant challenge, especially if the individual needs on-site support and financial assistance from government programs or private funds. Many of the aspects of living arrangements, such as decision-making authority and public assistance programs, are discussed in prior sections of this handbook.

Types of housing and living arrangements available to individuals with disabilities include the following:

- **Supported Living/Group Homes:** Supported Living Services (SLS) provides people with developmental disabilities with in-home support and in the communities where they live. With this service, people live in a home with other individuals who have intellectual or developmental disabilities. The home has around-the-clock staff to provide assistance, support, and safety for the residents.
- **Independent Living:** Provides support and services for individuals with I/DD so that they can live independently in their own home without 24/7 support.
- **Family Living:** Provides the opportunity to live in a typical family setting when residential habilitation is needed. Services and support are provided by a natural family member, host family member, or companion.

# 6. Financial Arrangements

## Special Needs Trust

A special needs trust (SNT) is a trust that will preserve the beneficiary's eligibility for means-tested government benefits, such as Medicaid and Supplemental Security Income (SSI). Because the beneficiary does not own the assets in an SNT, those assets do not "count against" the beneficiary for benefit programs that have an asset limit. As a general rule, the SNT trustee will use trust assets to supplement the beneficiary's government benefits but not replace them. Examples of supplemental needs include the cost of caregivers and companions, as well as dental or medical expenses not covered by Medicare or Medicaid. In many cases, the SNT will provide for payment of activities and expenses that provide a better quality of life for the beneficiary, such as paying for social events, leisure travel, and hobbies.

A complete description of the types, features, and uses of SNTs is beyond the scope of this handbook, so please refer to other numerous resources regarding SNTs offered by the Special Needs Alliance and consult with a Special Needs Alliance member attorney for advice about your particular circumstances.

## ABLE Accounts

### What is an ABLE account?

- Created by the 2014 ABLE Act (**A**chieving a **B**etter **L**ife **E**xperience Act), ABLE accounts are tax-advantaged savings accounts for individuals with disabilities. The beneficiary of the account is considered to be the account owner, and the income earned in the account is not taxed.

- Contributions to an ABLE account, which can be made by any person (the account beneficiary, family, friends, a special needs trust) must be made using after-tax dollars and will not be tax-deductible for purposes of the federal income tax; however, some states may allow income tax deductions for contributions made to an ABLE account.
- Eligible individuals and their families can establish ABLE accounts that will not affect the individual's eligibility for SSI, Medicaid, and other means-tested programs.

## Why are ABLE accounts needed?

- Individuals with disabilities and their families often depend on a wide variety of public benefits for income, healthcare, and food and housing assistance. Financial eligibility for many of these public benefits restricts individuals to $2,000 in countable resources, such as non-ABLE checking and savings accounts and some retirement accounts.
- To maintain eligibility for these public benefits, an individual must remain under the resource limit. The ABLE Act recognizes the extra and significant costs of living with a disability, including accessible housing and transportation, personal assistance services, assistive technology, and healthcare not covered by insurance, Medicaid, or Medicare. An ABLE account allows eligible individuals to save for some of these expenses.

## Who is eligible for an ABLE account?

- Prior to January 1, 2026, an individual whose disability began before the age of 26 was eligible to establish an ABLE account. If someone meets the age requirements and is also receiving benefits under SSI and/or SSDI, they are automatically eligible to establish an ABLE account.
- If the beneficiary is not a recipient of SSI and/or SSDI but still satisfies the disability onset date requirement, they are eligible if they meet Social Security's definition and criteria regarding functional limitations, and they receive a written disability certification from a qualified healthcare provider, such as a licensed physician.
- The beneficiary of an ABLE account does not need to be younger than the eligibility age at the time the account is created. Rather, the eligibility age relates to the onset of the disability, even if the ABLE account is established years, or even decades, after the disability began.

## What are the limits on an ABLE account?

- The total annual contributions to an ABLE account from all sources combined are limited each year and adjusted annually. (For 2026, that amount is $20,000.) Certain additional amounts may be deposited if the ABLE account beneficiary has earned income and does not participate in the employer's retirement plan, if any.
- The total lifetime limit on contributions to an ABLE account is the state's limit for education-related savings accounts ("529 Plans"), which range from approximately $250,000 to $550,000. However, for individuals who wish to continue receiving their SSI payments, the ABLE Act limit is effectively $100,000.
- If an ABLE account balance, when combined with the beneficiary's other resources, exceeds $100,000, the beneficiary's SSI cash benefit payment is suspended. When the value of the beneficiary's resources decreases below $100,000, SSI benefits are reinstated.
- While the beneficiary's eligibility for the SSI cash benefit is suspended, they remain eligible for medical assistance through Medicaid.

### What else do I need to know about ABLE accounts?

- Each eligible beneficiary is limited to only one ABLE account.

- An ABLE account may be used for a "qualified disability expense," which may include education, food, housing, transportation, employment training and support, assistive technology, personal support services, healthcare expenses, financial management and administrative services, and other expenses which help improve health, independence, and/or quality of life.

- Any funds remaining in an ABLE account at the beneficiary's death may be subject to a Medicaid claim for reimbursement for Medicaid benefits the beneficiary received after establishment of the ABLE account. Some states have eliminated this claim and other states are not placing a lien on the accounts. It is important to understand the rules in your state. Individuals can also name beneficiaries of their ABLE accounts.

- An eligible beneficiary may open an ABLE account in any state that has an ABLE program, if the program accepts out-of-state beneficiaries.

- An ABLE account may provide more choice and control for the beneficiary and their family than a special needs trust. The cost of establishing an ABLE account will likely be considerably less than the expense of establishing a special needs trust. The ABLE account owner controls the account, versus a trustee managing a special needs trust. In many cases, an ABLE account is a significant and viable option in addition to, rather than instead of, a special needs trust. Determining which options are most appropriate will depend upon individual circumstances.

Individuals can better manage their SSI/SSDI payments by having the SSA direct deposit their monthly check into their ABLE account.

## Social Security Representative Payee

For any type of Social Security benefit, the Social Security Administration may appoint a Representative Payee (Rep Payee) to manage the beneficiary's Social Security cash benefits, if the Social Security Administration has determined that the beneficiary is not able to do so themselves.

### Who may be the Rep Payee?

A Rep Payee can be an individual or an organization.

### How does someone get appointed as a Rep Payee?

Upon the written request of a beneficiary (or their legal representative) who is entitled to receive a Social Security cash benefit (but who cannot manage; or direct the management of those benefits), the Social Security Administration will appoint a Rep Payee to receive and manage the Social Security cash benefits for the beneficiary.

### What are the duties of a Rep Payee?

A Rep Payee's main duties are to use the cash benefits to pay for the current and future needs of the beneficiary, and to save any benefits not needed to meet current needs. A Rep Payee must also keep records of expenses. A Rep Payee must provide an annual accounting to the Social Security Administration describing how he or she used or saved the benefits.

## Is a Rep Payee the same as a POA?

A person's status as the beneficiary's authorized representative, power of attorney, or co-owner with the beneficiary of a joint bank account does not entitle a person to serve as the beneficiary's Rep Payee. These other arrangements do not give a person legal authority to negotiate and manage the beneficiary's Social Security benefits. To be a Rep Payee, a person must apply for and be appointed by the Social Security Administration in the separate capacity of Rep Payee.

# 7. Reporting Changes to SSA

SSA requires beneficiaries to report any change that could affect eligibility or payment amount. Failure to report can trigger overpayments, penalties, or sanctions.

Changes that must be reported to SSA are:

- **Financial & Resource Changes**. This includes any change in earned income (wages, self employment), any change in unearned income (pensions, unemployment, gifts, child support, etc.), any change in resources (bank accounts, vehicles, property, settlements) and changes in spouse's or parents' income/resources if applicable;
- **Living Situation**. This includes changes to one's address, changes in living arrangements (who you live with, who pays what), changes in help with food or shelter from others and when a death of someone in the household occurs;
- **Legal or Status Changes**. This includes changes in marital status, changes in citizenship/immigration status, if you leave the U.S. for 30+ consecutive days and if there is a felony warrant for escape/flight;
- **Institutionalization**. This includes admission or discharge from the hospital, nursing home, jail or prison;
- **Disability Related**. This includes changes to or improvement in one's medical condition, and PASS plan changes;
- **Work Changes**. This includes starting, stopping or changing work, changes to ticket to work program, a change in hours, duties or pay, and the receipt of any work's compensation, unemployment or other benefits.

Changes must be reported within 10 days after the end of the month in which the change occurred for SSI recipients, and as soon as possible for SSDI recipients. Changes can be reported online, by phone, by mail, or in person at the SSA office.

# 8. Additional Resources

Special Needs Alliance: www.specialneedsalliance.org

Social Security Administration: www.ssa.gov

National Guardianship Association: www.guardianship.org

ABLE National Resource Center: www.ablenrc.org

US Department of Education: www.ed.gov

Local Department of Health, Medicaid Services Department


www.specialneedsalliance.org