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What You Need to Know About Being an Adult with Disabilities

A HANDBOOK FOR SELF-ADVOCATES, PARENTS, GUARDIANS, AND THEIR LOVED ONES

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1 Introduction and Definition of Terms

INTRODUCTION

Supportive services and legal arrangements are only part of a person's transition to adulthood. Relationships, school, and housing involve additional perspectives that require coordination and understanding. Legal services should foster independence. Often, when the parents are the attorney's clients, it is easy to jump to the most protective arrangements that give the parents maximum control (e.g., guardianship, etc.). However, finding the best balance between autonomy and protection is important. For parents of children who are 16, 17, or 18 years old, legal and social services professionals can assist in achieving an appropriate balance between protection and independence.

The intent of this handbook is to explain some of the terms related to services and supports for people with disabilities, to introduce the process of transitioning from child services to adult services, and to provide guidance on options and resources that may be available to young adults with disabilities.

Because many laws are state specific, such as statutes regarding powers of attorney and guardianship, the reader is advised to seek legal counsel in their state. In some cases, this guide refers to uniform laws prepared by the Uniform Law Commission, and those uniform laws may be adopted by various states, often with additional state-specific amendments.

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 a 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) 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) 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 a 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 some people 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 financial help to disabled adults and children who have limited income and resources.

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. 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, caregiving, day services, supported employment and therapies. Because it is a Medicaid program, the services provided to those receiving this benefit 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 case and report its 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 given to an individual 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 conservatorship in some states) when a court determines they have a disability that prevents them from exercising judgment or if the person becomes overly reckless or harmful to their welfare.
- **Conservatorship:** The legal role given to an individual 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 estate" for a court-appointed party to manage someone's financial matters.
- **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 such will vary from state to state.
- **Surrogate Decision Maker:** A decision maker for a patient who is unable to speak 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

Supported decision-making is a concept where an individual, who is presupposed to have capacity, maintains full decision-making authority and includes others to assist in gathering and evaluating information to make decisions about healthcare, living arrangements, and money matters. Supported decision-making arrangements can be informal, like when many of us seek advice from family and friends. In addition, a growing number of states have adopted statutes to formalize supported decision-making with written agreements.

In general, a written supported decision-making agreement includes the following:

- The individual's name and the name of the supporter;
- The duration of the agreement, which can be for a limited period or with no end date;
- The types of information the supporter can access, such as financial, educational, or medical; and,
- Any other documents to authorize the release of information, such as the Family Educational Rights and Privacy Act (FERPA) release for educational information or Health Insurance Portability and Accountability Act (HIPAA) release for medical information.

In addition to a supported decision-making agreement, it is a good idea for an individual to have power of attorney for healthcare and a financial power of attorney, in case the individual ever becomes incapacitated.

Powers of Attorney (Uniform Power of Attorney Act)

- Requirements for a Power of Attorney (POA) to be valid:
  - **i.** The principal must have capacity;
  - **ii.** It must be in writing;
  - **iii.** It must be signed by the principal; and,
  - **iv.** It must be notarized and may also need to be witnessed.
- Durable Power of Attorney
  - **i.** If a POA is "durable," it continues to be valid even if the principal becomes partially or fully incapacitated.

ii. If the POA is not durable, it only authorizes the agent to make decisions for the principal when the principal has the capacity to direct or authorize the agent's action. If the principal becomes incapacitated, the agent loses authority to make decisions for the principal.

iii. In many cases, a POA is effective immediately so that the agent may begin acting on behalf of the principal as soon as the POA is executed.

iv. Alternatively, a "springing" POA does not allow an agent to make decisions for the principal unless and until the principal is determined incapacitated. Usually this requires written documentation of incapacity by two healthcare providers, one of whom generally needs to be the principal's primary care provider.

- Duties, Responsibilities, and Limitations of a Financial POA

  i. Typically, 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.

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

    1. Create or change beneficiaries;
    2. Alter rights of survivorship;
    3. Give gifts;
    4. Make changes to an inter vivos (living) trust;
    5. Further delegate the authority created by the POA;
    6. Control the principal's electronic communications; or
    7. Waive certain entitlements for the principal.

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

    1. 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;
    2. Acting in good faith; and
    3. Acting only within the scope of authority granted in the POA.

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

    1. Act loyally for the principal's benefit;
    2. Act without creating a conflict of interest that impairs the agent's ability to act impartially in the principal's best interest;
    3. Act with the care, competence, and diligence ordinarily exercised by agents in similar circumstances;
    4. Keep a record of all receipts, disbursements, and transactions made on behalf of the principal;
    5. Cooperate with a person that has 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
    6. 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.

- Duties, Responsibilities, and Limitations of a Healthcare POA:
  - **i.** Typically, an agent under a healthcare POA is responsible for making decisions regarding the agent's care including consenting or to medical treatment, medical testing, medical procedures, and surgical procedures. The agent may be responsible for making decisions regarding medications, residential placement, social activities, and interactions with family and friends.
  - **ii.** If the document includes an end-of-life directive, the agent may also have the responsibility to enact the principal's wishes.
  - **iii.** Unless related to the principal by blood, marriage or adoption, an agent typically may not be an owner, operator, or employee of a healthcare institution at which the principal is receiving care.
  - **iv.** An agent shall make healthcare decisions in accordance with the principal's individual instructions, if any, and other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent's determination of the principal's best interest. In determining the principal's best interest, the agent shall consider the principal's personal values to the extent known to the agent.
  - **v.** A written advance healthcare directive may also include the principal's nomination of a guardian of the person.

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 look out for 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 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 be without any long-term oversight of such an arrangement.

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

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 minor children)

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

- Guardians often make decisions similar to those that a healthcare power of attorney would make such as consent to or refusal of medical treatment, medical testing, medical procedures, and surgical procedures. The guardian may be responsible for making decisions regarding medications, residential placement, social activities, and interactions with family and friends.
- Guardians are often monitored by the court through regular written reporting or hearings.
- A guardian 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 a guardianship proceeding, there must be medical evidence to support the medical reason for the lack of capacity (i.e., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse).
- In many states, the alleged incapacitated person may also be represented in the guardianship proceeding by a Guardian *ad Litem* or by an attorney of their choosing or as appointed by the court.

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.

- 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 often monitored by the court through regular written reporting 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 a conservatorship proceeding, there must be medical evidence to support the medical reason for the lack of capacity (i.e., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse).
- 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 estate” for a party appointed by the court to manage someone’s financial matters.

3 Benefits and Services

Medicaid Waivers

Medicaid benefits are administered by each state, based on a combination of federal and state funding and federal and state laws for administering the programs. 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 for 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 a waiver program, an application must be filed with the state agency that administers the program. Often supporting documentation will be required such as 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 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. Supported living; family living; independent living;
    9. Community supports services (sometimes known as "day hab"); and
    10. 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 allocation of services; and
  - Eligibility is typically based upon the Social Security standard for "disability" along with a financial eligibility requirement.

Social Security: SSI and SSDI

These benefits are received directly from the federal government through the Social Security Administration. 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." If an individual is 18 years or older, only their income is counted toward determining financial eligibility.

Applications for these benefits are submitted through the Social Security Administration's website. Documentation to prove the disability and financial eligibility will be required.

Supplemental Security Income (SSI)

SSI is a cash program. Every eligible individual receives the same amount of money each month regardless of the nature of the qualifying disability, the level of their needs, and the city and state in which they reside. Eligibility for SSI:

- Over age 65; or blind or disabled;
- Limited income and resources;
- U.S. citizen or national, or in one of certain categories of aliens;
- Resident of one of the 50 states, the District of Columbia, or the Northern Mariana Islands; and
- Is not confined to an institution (such as a hospital or prison) at the government's expense.

What does "disabled" mean for SSI 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"?
  - Money earned from work;
  - Money received from other sources, such as Social Security benefits, workers compensation, unemployment benefits, the Department of Veterans Affairs, friends, or relatives; and
  - Free food or shelter.
- What is considered a "resource"?
  - Cash;
  - Bank accounts;
  - Stocks, mutual funds, and U.S. savings bonds;
  - Land;
  - Vehicles;
  - Personal property;
  - Life insurance; and
  - Anything else that the applicant owns that could be converted to cash and used for food or shelter.

Social Security Disability Income (SSDI)

The SSDI program pays cash benefits to the eligible worker and certain family members if the worker is "insured." This means that the worker worked enough quarters – and recently enough – and paid Social Security taxes on their earnings. The amount is based upon the number of "work credits" the worker has prior to becoming disabled. Eligibility for SSDI:

- Have worked in jobs covered by Social Security; and
- Have a medical condition that meets Social Security's definition of disability.
- There is no resource limit for receiving SSDI.

Disabled Adult Child (DAC):

Another type of SSDI benefit is called Disabled Adult Child benefits. An adult who has a disability that began before age 22 may be eligible for benefits 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 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")

What Is VR?

- Vocational Rehabilitation is the primary public program to support people with disabilities to achieve competitive employment outcomes.
- This program is usually run through the state government and may be a part of the state's education department, human services department employment division, or social services department.
- Often this service can be started when a person is in high school and by contacting the state vocational rehabilitation office.

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 experiences 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 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.

Care Management for the Special Needs Child Whether a Minor or Adult

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

- Support 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 all eligible waivers are applied for to facilitate funding for support; and,
- Additional activities, such as day programs, classes, and other resources are available.

It's important to create a transition plan for the adult child who lives at home but will need a new arrangement once parents are no longer able to provide the 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 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 child's Individualized Education Program (IEP). The need for ESY services must be determined annually on an individual basis by the individualized education program (IEP) team.

Who is eligible?

Eligibility for ESY services is assessed by a student's IEP team. An IEP or special education services 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 child's IEP team annually. Parents can request an ESY program through the child's school district or at the next IEP meeting. Similar to other decisions made by the school district, if a child 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 over the break. If the 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 child's progress will be significantly delayed when the 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 child 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 considered to be one form of employment in which wages are expected, together with benefits from an employer in a competitive workplace, though some versions refer to disability agency paid employment.

What are the key features of Supported Employment?

- Lend competence to the individual with disabilities until they learn the job.
- Be accountable for facilitating job opportunities.
- Target jobs that individuals with disabilities may not otherwise have knowledge of access.

What else is important to know?

- A supported employee can be the only employee with a disability in an organization.
- 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 picked up by the state developmental disability agency at the time period designated in the supported employment plan.

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 support in home 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

SNT

- A special needs trust (SNT) is a trust that will preserve the beneficiary's eligibility for needs-based government benefits, such as Medicaid and Supplemental Security Income (SSI). Because the beneficiary does not own the assets in the trust, he or she will be eligible for benefit programs that have an asset limit. As a general rule, the trustee will use trust assets to supplement the beneficiary's government benefits but not replace them. Examples of supplemental needs are costs for sitters, companions, and 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 special needs trusts offered by the Special Needs Alliance and consult with a Special Needs Alliance member attorney for advice about your particular circumstances.

ABLE

What is an ABLE account?

- Created by the 2014 ABLE Act (Achieving a Better Life Experience Act), ABLE accounts are tax-advantaged savings accounts for individuals with disabilities and their families. The beneficiary of the account is the account owner, and income earned by the account is not taxed.
- Contributions to the account, which can be made by any person (the account beneficiary, family, friends, special needs trust) must be made using post-tax dollars and will not be tax deductible for purposes of federal taxes; however, some states may allow for state income tax deductions for contributions made to an ABLE account.

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.
- Eligible individuals and their families can establish ABLE accounts that will not affect their eligibility for SSI, Medicaid, and means-tested programs.

Who is eligible for an ABLE account?

- An individual is eligible for an ABLE account if their disability begins before age 26. Effective January 1, 2026, an individual whose disability began before age 46 can establish an ABLE account. If someone meets this age requirement 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 meets the age of onset disability requirement, they are eligible if they meet Social Security's definition and criteria regarding functional limitations and receive a letter of disability certification from a qualified healthcare provider, such as a licensed physician.
- To establish an ABLE account, the beneficiary 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 are limited to the annual gift tax exclusion amount. (For 2023, that amount is $17,000.) Certain additional amounts may be deposited if the account beneficiary has earned income.
- The total lifetime limit is the state's limit for education-related 529 savings accounts, which range from approximately $250,000 to $550,000. However, for individuals who receive SSI, the ABLE Act limit is $100,000.
    - If an ABLE account balance, when combined with other resources, exceeds $100,000, the beneficiary's SSI cash benefit is suspended. When resources return below $100,000, benefits are reinstated without a time limit.
    - 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 reimbursement to states' Medicaid programs as payback for Medicaid benefits the beneficiary received after establishment of the ABLE account. This payback requirement is an important consideration for individuals other than the beneficiary who wish to contribute to an ABLE account. (Although payback or recovery from a beneficiary's trust or estate is common in most state's Medicaid programs, some states currently do not seek payback from ABLE accounts.)
- An eligible beneficiary may open an ABLE account in any state that has an ABLE program, so long as 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 account will likely be considerably less than 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 and combinations are most appropriate will depend upon individual circumstances.

Social Security Representative Payee

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

Who may be the Payee?

- A representative payee can be a person or an organization.

How does someone get appointed as a Rep Payee?

- The Social Security Administration appoints a payee to receive the Social Security or SSI benefits for anyone who can't manage or direct the management of his or her benefits.

What are the duties of a Rep payee?

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

Is a Rep Payee the same as a POA?

- Being an authorized representative, having power of attorney, or a joint bank account with the beneficiary is not the same as being a payee. These arrangements do not give legal authority to negotiate and manage a beneficiary's Social Security and/or SSI benefits. To be a Pre Payee, an individual must apply for and be appointed by the Social Security Administration.

7 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