

Supported Decision Making and For Adults with Disabilities



DISABILITY RIGHTS
PENNSYLVANIA

Freedom to Make Decisions

- Historically, people with disabilities were presumed unable to make decisions
 - Many people with disabilities lived in institutions
 - Decision-making in institutions is usually unnecessary
 - Institutional care perpetuated dependence on others to make decisions
- Today, integration is the norm
 - Most people with disabilities live in the community
 - Decision-making by people with disabilities – everyday decisions, personal decisions, financial decisions, healthcare decisions – has become an issue of increasing concern

Freedom to Make Decisions

- Adults – even adults with disabilities – have the right and are presumed to have the capacity to make their own decisions
- Freedom to make decisions is fundamental to personal autonomy and self-determination
- An adult’s right to make their own decisions can sometimes be limited
 - People with disabilities may need supports to help them understand and make decisions and, often, “supported decision-making” will be effective
 - Sometimes, however, people with disabilities may need others to make a decision for them. These are often called “substitute decision-makers”

Consent and Capacity

- “Consent” and “capacity” are key issues that inform questions of decision-making
- Whether people have the “capacity” to provide “consent” is usually determinative of whether they can make their own decisions
- Consent
 - Simple consent – Decisions relating to routine matters that pose no risk of harm greater than that normally encountered in daily living
 - Informed consent – Decisions that have greater risks and consequences than those generally encountered in daily life

Consent and Capacity

- Whether an adult can provide the necessary level of consent depends on their “capacity”
- Capacity to consent means that the individual:
 - Possesses the ability to understand the situation, the alternative options, and the risks and benefits
 - Possesses the ability to use the information in a logical and rational way to reach a decision
 - Can communicate the decision (verbally or otherwise)
- A diagnosis of intellectual disability, autism, dementia or other cognitive disabilities does not mean that a person lacks capacity to make all decisions

Beyond Consent and Capacity

- There are certain situations in which consent and capacity are not necessarily determinative of who can or should make decisions:
 - **Medical emergencies** – A physician can perform emergency medical procedures when a person is unconscious and cannot give consent if delay is a threat to the person's life or health absent known instructions to the contrary
 - **Financial management** – Large sums may need to be placed in a trust managed by a third-party to protect the individual's right to receive government benefits, including Medicaid
 - **Fundamental rights** – Decisions involving fundamental rights (e.g., marriage, sterilization, abortion, termination of parental rights, involuntary commitment, voting) either can only be made by the individual (regardless of capacity) or can be made by a substitute decision-maker only upon a specialized showing

Decision-Making Considerations

- Whether a person has the capacity to consent to any particular decision requires an individualized determination and consideration of the following factors:
 - Nature of disability
 - A disability by itself is not determinative of decision-making capacity
 - Even people with cognitive disabilities have wide variation in abilities
 - Nature of the decision
 - The level of capacity will vary depending on the level of consent necessary
 - Decision-making is not an all-or-nothing proposition – a person may be able to make some decisions, but not others
 - Individual's decision-making experience
 - It is important that people with disabilities have experience to the maximum extent possible in making decisions that impact their own lives
 - Existence of natural supports
 - Family members, friends, and lay advocates can assist individuals to make their own decision

Alternatives to Guardianship

- Supported Decision-Making
- Substitute (Surrogate) Decision-Making Other than Guardianship
 - Health Care
 - Health Care Agents (Health Care Advance Directives)
 - Mental Health Care Agents (Mental Health Advance Directives)
 - Health Care Representatives
 - MH/ID Providers
 - Financial
 - Representative Payees
 - ABLE Accounts
 - Financial Agents (Financial Powers of Attorney)
 - Trustees
- Protective Services
 - Older Adult Protective Services Act
 - Adult Protective Services Act

Substitute vs. Supported Decision-Making

- Substitute decision-making
 - Grants decision-making authority to another person
 - Takes legal authority away from individuals with disabilities if they are determined not to have legal capacity
 - Many forms of substitute decision-making
- Supported decision-making
 - Recognizes that we all make decisions with the support of others, such as family, friends, professional advisors
 - Allows the individual with the disability to retain legal capacity to make decisions with support; the key is that the individual remains the decision-maker
 - More respectful of individual autonomy than substitute decision-making

Supported Decision-Making

- Allows people with disabilities to use family members, friends, advocates, and professionals to help them understand the situations and choices they face so they can make their own decisions
- Elements include:
 - Network of people who have an established, trusting relationship with the individual
 - Provision of information to understand options and consequences of decisions
 - Plain language/alternative formats
 - Accommodations to support decision-making
 - Ultimately, it is the individual with the disability who is the decision-maker
- More information:
 - National Resource Center for Supported Decision Making, <http://www.supporteddecisionmaking.org/>
 - Center for Public Representation, <https://supporteddecisions.org/>

Supported Decision-Making in Pennsylvania

- Pennsylvania law does not expressly recognize any formal type of supported decision-making
- Informal supported decision-making, however, does have relevance in Pennsylvania
 - *In re Peery* – PA Supreme Court held that the availability of natural supports overrides the need for guardianship
 - The recognition and use of natural supports in the disability service systems
 - Natural supports are used by many individuals with disabilities to help with daily life decisions

Limits on Supported Decision-Making in Pennsylvania

- With few exceptions, supported decision-making is not a legally recognized decision-making process in Pennsylvania
- Decision making with natural supports will not be effective if:
 - the person with the disability does not want their assistance;
 - there already is a legally recognized substitute decision-maker with authority to act; or
 - it is the type of decision that can only be made by legally authorized substitute decision-makers for individuals who lack capacity to make them
 - health care decisions requiring informed consent
 - financial decisions

Substitute Health Care Decision-Making: Health Care Advance Directives

- Types of Advance Health Care Directives:
 - Living Wills
 - End-stage medical disease or permanently unconscious
 - Need not have an agent appointed
 - Health Care Powers of Attorney
 - Not limited to end-of-life decisions
 - Must appoint agent who will execute the HCPOA in the event the person becomes incompetent
 - Combined Living Wills/Health Care Powers of Attorney
- Documents must comply with requirements of state law

Substitute Health Care Decision-Making: Health Care Advance Directives

- Adults age 18 or older who are of “sound mind” can execute Advance Health Care Directives
 - “Sound mind” means the ability to make an informed decision about the matters covered by the Advance Health Care Directive
 - Some individuals with cognitive disabilities can make Advance Health Care Directives
 - Important for family members, health care providers, supports coordinators, and others involved with aging individuals to encourage them to execute health care advance directives

Substitute Health Care Decision-Making: Health Care Representatives

- Health care representatives can make health care decisions for individuals when:
 - their attending physicians determine that they are not competent to make a health care decision;
 - they are 18 years old or they graduated from high school or married or they are emancipated minors;
 - they do not have a guardian of the person authorized to make health care decisions; and
 - they either do not have Advance Health Care Directives or the health care agents appointed under the Directives are not willing to act and there are no alternative health care agents

Substitute Health Care Decision-Making: Health Care Representatives

- Individuals of sound mind can identify the persons they want to serve as their health care representatives in the event they become incompetent
 - Write and sign document with designation
 - Tell attending physician or health care provider
- Absent designation, law specifies who can serve as a person's health care representative in the following order of priority:
 - Spouse and adult children who are not children of spouse
 - Adult children
 - Parent
 - Adult sibling
 - Adult grandchild
 - Adult with knowledge of individual's preferences and values, including religious and moral beliefs
- Attending physician or health care provider or provider's employees cannot act as a person's health care representative

Substitute Health Care Decision-Making: Health Care Representatives

- Limits on health care representatives' authority
 - Cannot refuse life-preserving treatment for person who does not have end-stage disease or who is not permanently unconscious
 - There may be other limits similar to limits imposed by law on guardians, including:
 - Removal of healthy bodily organ
 - Experimental treatment
 - ECT
 - Commitment to psychiatric hospital or state center

Substitute Financial Decision-Making: Representative Payees

- Appointed by the Social Security Administration to receive an individual's SSI benefits or SSDI benefits
 - SSA conducts an investigation to assess the individual's ability to handle their money and whether appointment of a Representative Payee is in their interest
 - It is not necessary for a Beneficiary to be adjudicated incapacitated to have a Representative Payee appointed
- Representative Payees must use the benefits to:
 - first, pay for the individual's current needs (e.g., housing, food, utilities, health care, clothing, personal care)
 - second, once those expenses are paid, pay any past-due bills, to support any dependents, or pay for entertainment for the individual
 - third, save any funds remaining after those expenses are paid for the individual

Substitute Financial Decision-Making: Representative Payees

- Who can serve as a Representative Payee
 - Prefer a person who knows the beneficiary (e.g., family member, friend, attorney)
 - In absence of such an individual, SSA can appoint social service agencies
 - Certain people are disqualified from serving as Representative Payees, including creditors of the beneficiary, providers, and people who have been convicted of certain crimes
- Removing the Representative Payee
 - Problems or concerns regarding the Representative Payees should be reported to SSA
 - SSA will investigate to determine whether the Representative Payee should be removed and/or a new Representative Payee appointed

Substitute Financial Decision-Making: PA ABLE ACCOUNTS

- PA ABLE accounts allow individuals with qualifying disabilities to save without risking loss of their SSDI, SSI, Medicaid, and certain other benefits
- To qualify, a person must receive SSDI or SSI due to blindness or disability (or self-certify that they have a similarly severe disability) and the disability must have started before age 26
- Individuals, family members, and friends can contribute to ABLE accounts
- Up to \$16,000 a year can be added to ABLE accounts (though that a total of \$28,880 can be contributed if the individual contributes earned income) but accounts cannot exceed \$511,758 and if accounts exceed \$100,000 the individual will lose SSI eligibility
- There are various investment options available
- Account funds can be used for “qualified disability expenses,” which include, among other things, education, vocational training and support; housing; transportation; healthcare; and legal fees
- Account holders may have fiduciaries manage their accounts for them if they choose
- More information about PA ABLE Accounts can be found at <https://www.paable.gov/>

Substitute Financial Decision-Making: Financial Powers of Attorney

- A person (the principal) who is of “sound mind” can create a Financial Power of Attorney (FPOA) which appoints another person (the agent or attorney-in-fact) to handle mainly financial decisions
- An FPOA must comply with requirements of state law
- The FPOA will state when it becomes effective (often only when the principal becomes incompetent)
- The FPOA must state if it is durable or not durable, though a principal who is competent always can revoke it
- The FPOA must identify the agent’s powers, which can include:
 - Financial issues (e.g., bank accounts, real estate, investments, retirement accounts)
 - Some health care decisions, such as admitting the principal to a nursing home

Substitute Financial Decision-Making: Trusts and Trustees

- A trust is a legal instrument where a person (the settlor) places money or other property (the trust assets) in a special account for the benefit of one or more persons (the beneficiaries). A third-party (the trustee) is designated to control the assets in accordance with specific directions in the trust
- Trusts can be important for individuals to qualify for or maintain needs-based government benefits, such as SSI or Medicaid
 - Not all trusts will protect an individual's eligibility for government benefits
 - Important to have careful legal advice, particularly for older adults where placing money in a trust may have negative consequences related to asset transfers

Protective Services: Covered Misconduct

- The protective services processes under Adult Protective Services and Older Adult Protective Services may be triggered by:
 - Abandonment
 - Abuse
 - Sexual Abuse
 - Neglect
 - Self-neglect
 - Caregiver neglect
 - Financial Exploitation
- Environmental factors outside the control of the person or their caretaker (e.g., income, inadequate housing or medical care) are not covered by the statutes

Protective Services: Reporting

- Hotline for APS and OAPSA: 800-490-8505
- Voluntary reporting
 - Anyone who has cause to believe that an adult with a disability or an older adult needs protective services can make a report by calling the hotline
- Mandatory reporting
 - Employees or administrators of certain facilities (e.g., nursing homes and personal care homes) and providers (e.g., home health agencies) are required to make reports when they suspect that an adult with a disability or an older adult has been a victim

Protective Services: Investigations, Assessments and Service Plans

- Reports are screened and categorized
 - No need
 - Need
- Investigations of reports other than “no need”
 - Substantiated (person needs protective services) or
 - Unsubstantiated (person does not need protective services)
- Assessments for protective services in substantiated cases
- Develop protective service plan
- Arrange for provision of services

QUESTIONS?



Contact Information

Disability Rights Pennsylvania

Intake: 800-692-7443, ext. 400 (voice)

Intake: 877-375-7139 (TDD)

Intake: intake@disabilityrightspa.org

Website: www.disabilityrightspa.org