

Promoting Autonomy for Older Adults and Adults with Disabilities through Decisional and Other Supports

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Introduction

The ability to make decisions is a fundamental human right and one of the hallmarks of what it means to be an adult. When an individual turns eighteen, the law says that individual is now able to control their own life. They get to make decisions about where and how to live, who they want to associate and socialize with, how they want to spend their time and money, what they want to eat and wear, and even what happens to their bodies (the health care they receive). The ability to make decisions about one's own life, to be self-governed and self-directed, is called autonomy. Autonomy, simply put, is the ability make choices yourself rather than having them made for you by other people.

Being autonomous, though, does not mean maneuvering through life without help. Indeed, most people are constantly supported in their daily lives by family, friends, community, technology, professional advisors, and all manner of other supports and supporters. Those various supports might range from the simple advice of a friend to the more formal advice of a doctor or lawyer or the help provided by an agent under a power of attorney. The term “decisional supports” is used to encompass all those means of support, from informal interactions to more formal practices.

All individuals need support now and then. And because people are all different, some might need more support than others. What supports are needed will depend on an individual's circumstances, preferences, abilities, resources, life experiences, and culture. All decisional supports should be person-centered and person-directed, meaning the values, priorities, and wishes of the individual should drive the decision-making process.

For older adults and adults with disabilities, obtaining needed supports and building a trusted network of supporters might mean the difference between retaining or losing autonomy. Advocates who assist these adults (who are, in fact, themselves supports and supporters) should, therefore, think of the various supports discussed below (and others) as helpful mechanisms that, with the participation and consent of the adult, can be identified and implemented to preserve autonomy and maintain independence.

Remember, though, that identifying and implementing supports is not just selecting from a menu. It's a process. One that entails identifying the specific issue (or issues) to be addressed; understanding the values, priorities, and wishes of the individual; then applying creative combinations of supports and supporters, often through trial and error, to target the individual's issues and meet the individual's goals, all while maintaining open dialogue and keeping the individual firmly in the driver's seat.

Supported Decision-Making

Supported decision-making is the process by which an adult selects trusted supporters to help them as needed to understand issues, options, risks, and consequences; empower the adult to make choices; and assist as asked and needed to carry out those decisions. Supported decision-making can be informal, like asking a plumber to explain a problem, provide repair options, and share recommendations to help make a choice. Or it might be more formal, such as a written agreement detailing the issues the adult might want help with, the types of help they want, and who they want to help them. The focus should be on the process of helping the adult understand and make choices, not on the formality of the arrangement. The process of supported decision-making can (and should) also be incorporated into the other support mechanisms discussed below.

Tips for Building a Support Network

Building a support network involves identifying and working with others who will collectively function as a team to provide support making decisions, always with the adult in need of supports as their leader.

1. **Identify potential supporters:** The process of building a support network might start with drafting a list of trusted family members, friends, neighbors, and other community members and professionals the person interacts with on a regular basis. Remember, it's important to look beyond cultural assumptions of who may be a family member or a friend.
2. **Discuss relationship dynamics:** Sometimes the adult in need of support has family or friends they have little or no contact with. Ask about those relationships and if it is okay to reach out. Sometimes cutting off contact is intentional, and sometimes it just happens because of time, distance, or different interests. Distant family and friends are sometimes eager to reestablish a relationship and sometimes not.
3. **Spread a wide net:** Ask about neighbors, current or past co-workers, service providers, caregivers, connections with local community organizations or faith communities, and trusted professionals.
4. **Focus on trust:** The supporters selected must be trusted by the adult in need of support. Otherwise, those people are not supporters.
5. **Consider professionals, volunteers, and nonprofits:** Supporters can also be professionals. Social workers, nurse care managers, and professional money managers can all be successful supporters. If the adult can afford to pay, they can hire a professional support team. If payment is not an option, look to local volunteer and government services for potential supporters.
6. **Verify commitment:** Everyone on the support team should be committed to the person-centered and person-driven model at the heart of supported decision-making. Help the adult identify supporters who are willing to be involved long-term, who are flexible and open to new ideas and ways to support, and who accept and honor the person's abilities and integrity of choice.

Remember also that a support network is not a fixed system or group. Different team members play different roles in supporting the person. The team is expected to evolve, change, and grow just as the person's abilities, needs, and goals change. Once a core group is established and the team members get to know each other and learn how they best work together, members can more easily adapt to those changes in team structure and the person's needs.

Resources for Supported Decision-Making

- [Getting Started with Supported Decision-Making](#), Center for Public Representation
- [How to Make a Supported Decision-Making Agreement](#), American Civil Liberties Union
- [National Resource Center for Supported Decision-Making](#)
- [Supported Decision Making](#), American Bar Association
- [Supported Decision-Making: Frequently Asked Questions](#), American Civil Liberties Union
- [Supported Decision-Making: What Is It and What Do You Need to Know to Get Started?](#), The Arc

Supports for Health Care Decisions

A health care surrogate is a person who makes health care decisions for an individual when that individual lacks the ability to make health care decisions. A surrogate may also be called a health care agent or proxy. In every state, an adult with the requisite decisional capability can appoint a health care surrogate in a durable power of attorney that includes health care authority. Some states have even developed health care power of attorney forms specifically for adults with dementia and adults with intellectual disabilities. Many states have a short form for naming a health care surrogate. An adult can typically appoint a health care surrogate if the adult understands what a health care decision is and can name a trusted person to make those decisions.

If an adult does not appoint someone, a majority of states have statutes that give guidance on who can make health care decisions. Generally, statutes turn to the nearest relatives to make decisions.

The authority of a health care surrogate to make decisions does not start until the adult loses the ability to make decisions (as determined by the adult's health care provider) or knowingly defers to the surrogate. The scope of the surrogate's authority is defined in the document and by state law. As long as the adult has the requisite decisional capability, the adult can revoke or modify the appointment of a surrogate. Many states have a very low standard of decisional capability for revocation.

Aside from leaving directions on who can make health care decisions, many adults leave directions about the health care they want or do not want in the form of an advance directive or living will directive. When making health care decisions for another person, it is helpful to understand their health care values, goals of care, and specific wishes.

Resources for Health Care Decision Supports

- [Choosing a Health Care Proxy](#), National Institute on Aging
- [Find Advance Directives Forms by State](#), AARP
- [Find Home Health Services Near Me](#), Medicare
- [Geriatric Care Managers Advocate for Older Adults – and Their Caregivers](#), AARP
- [Giving Someone a Power of Attorney for Your Healthcare \(Multi-State Guide and Forms\)](#), American Bar Association
- [Health Care Decision-Making](#), American Bar Association
- [How Geriatric Care Managers Can Help Family Caregivers](#), AARP
- [Living Wills, Health Care Proxies, & Advance Health Care Directives](#), American Bar Association
- [Power of Attorney](#), American Bar Association
- [What Is a Geriatric Care Manager?](#), National Institute on Aging
- [Your Guide to Choosing a Health Care Proxy](#), The Conversation Project

Supports for Financial Decisions

Power of Attorney

A power of attorney is a legal document. The document grants one person, generally called an agent, sometimes known as an attorney-in-fact, the authority to act on behalf of the adult appointing them. The adult appointing the agent is called the grantor, sometimes known as the principal. To create a power of attorney, the adult must be able to understand they are appointing an agent and understand the types of authority they are giving the agent. The scope of the agent's authority is limited by the terms of the document and by state laws. Copies of the executed document should be given to the agent and other people and institutions the grantor might deal with on a regular basis, such as health care providers and banks. A grantor can revoke or modify the appointment of an agent in a power of attorney. Revocation of a power of attorney should be in writing, signed by the grantor, with a copy delivered to the agent and anyone who is likely to be dealing with the agent. In some states, the revocation needs to be recorded in the public records like a deed.

Tips for Selecting an Agent for Finances or Health Care

A power of attorney can be executed to appoint an agent to handle financial issues or to make health care decisions. Selecting the right agent – someone who is trustworthy and sure to respect the wishes of the grantor – is critical and can mean the difference between success and failure of the tool.

1. **Prioritize honesty and reliability:** An agent who has authority over an adult's money or health care must be trustworthy. The agent selected should have a history of honesty and reliability in performing tasks that need attention, from paying bills to scheduling appointments and communicating with professionals.
2. **Verify respect for preferences:** An agent should prioritize the grantor's wishes over their own and make choices that align with the grantor's values. The agent must be able to understand the grantor's beliefs and attitudes toward money, health care, illness, and death. And, importantly, the grantor must be comfortable discussing those issues with the agent.
3. **Consider proximity:** Depending on the situation, an agent may need to show up quickly in an emergency. Choosing someone who lives out of state may not be the best choice if another candidate lives nearby.
4. **Focus on communication skills:** Good speaking skills, confidence, assertiveness, and a calm demeanor under pressure are all excellent qualities for an agent. Think about the person's communication style. The agent selected should be able to communicate the grantor's wishes clearly and effectively and not back down under pressure when it comes to supporting the grantor's goals.
5. **Assess understanding:** Some knowledge about finances and how health care works will undoubtedly be helpful for the agent. This doesn't mean the grantor needs to select the doctor or lawyer in the family. Rather, the grantor should select someone who knows to ask the right questions.
6. **Gauge willingness to serve:** Being an agent or surrogate can be stressful and demanding, and not everyone is up to the task. The grantor should talk frankly to the person being considered and encourage them to be honest. The person should understand the role, as well as the grantor's wishes and goals, and be clear about the types of decisions they might need to make.

Bank Accounts

A common way to manage another person's finances is to authorize an agent to sign on that person's bank accounts. There are two ways to do this: (1) add a person authorized to transact business on the account, or (2) make the bank account a joint account. A joint account creates a presumption of ownership in the account assets and may create inheritance rights. Joint accounts are very helpful for married or committed couples. For more distant family members or friends, joint accounts should be used with great caution. Rather than create a joint account, the bank can authorize someone to sign on the account without creating an ownership interest in the account. This is most commonly done by the bank recognizing the authority granted under a financial power of attorney (discussed above). In many states, the bank may insist on a state standard form or a bank-approved power of attorney form. Banks can also authorize signers on accounts without creating an ownership interest, as they do for business accounts.

Additionally, many banks and financial institutions allow the account holder to designate a trusted person who the institution can contact if there is an issue with the account or suspected financial exploitation. The designation authorizes the institution to disclose account information to the trusted person and to confirm the account holder's contact information, health status, and the identity of anyone authorized to act on the account holder's behalf.

Direct Deposit and Automatic Payment

All Social Security benefits and virtually all retirement benefits are paid by direct deposit. Direct deposit eliminates the need to make deposits and prevents lost or stolen checks. Nearly all reoccurring bills can be set up on automatic payment. The combination of direct deposit and automatic payments can help to assure that necessary bills are paid when a person is unable to attend to finances. These arrangements should be monitored to assure that all income is properly received and automatic payments are correct. Increasingly, financial institutions and utility providers are willing to send copies of invoices and statement to a third party or to arrange online access for account oversight.

Social Security Representative Payee

A Social Security Representative Payee (rep payee)¹ manages the benefits for a beneficiary who has been determined unable to manage money by the Social Security Administration (SSA). The rep payee will receive the monthly benefit payments and use them for the current needs of the beneficiary and in their best interests. All rep payees are volunteers, with an exception for narrowly defined nonprofits who are allowed to receive a limited fee from the benefits. In some states, inpatient residential settings, such as nursing homes, are allowed by state law or regulation to serve as representative payees. Most payees are required to file a basic annual accounting. Social Security does not recognize any other agents. Agents under powers of attorney and guardians must apply to Social Security to be recognized as a representative payee.

Social Security will place the benefits in payee status if SSA has reason to believe that the beneficiary is unable to manage benefits. The beneficiary can also request a rep payee voluntarily. The process is entirely administrative. Representative payee status can be terminated at the request of the beneficiary with proof that the beneficiary has regained the ability to manage benefits.

¹ Rep payee is specific to Social Security benefits, including disability benefits and Supplemental Security Income. VA benefits and some private pensions have separate payee systems.

Money Management and Bill Pay Services

Money management and bill pay services provide one-on-one assistance with financial management. Once engaged, the service will receive all paper and electronic bills, review and pay the bills, balance the accounts, and maintain all financial records. Some services might assist with creating a budget, gathering and organizing tax documents, and filing insurance claims. These services might be available for free or at a low cost, possibly staffed by volunteers, or they might charge an hourly or monthly fee.

Trusts

Finances can also be managed through the creation of a trust, a legal entity able to hold property and assets that is managed by a fiduciary (the trustee—someone appointed by the grantor to assist in managing the trust funds and assets) for the benefit of the beneficiary pursuant to the instructions in the trust documents. Trusts are typically established to control and manage assets while the person is alive and to provide for distribution of the estate after death.

Resources for Financial Supports

- [Can a Family Member or Friend Help Me with Bill Paying and Banking?](#), Consumer Financial Protection Bureau
- [Eldercare Locator](#), U.S. Administration on Aging
- [Identify Someone to Manage Benefits for You](#), Social Security Administration
- [Planning for Diminished Capacity and Illness](#), Consumer Financial Protection Bureau
- [Planning for Peace of Mind: Social Security Advance Designation](#), Consumer Financial Protection Bureau
- [Power of Attorney](#), American Bar Association
- [Drafting Advance Planning Documents to Reduce the Risk of Abuse or Exploitation](#), NCLER
- [Representative Payee](#), Social Security Administration
- [Thinking Ahead Roadmap: A Guide for Keeping Your Money Safe as You Age](#), AARP and University of Minnesota
- [Ways to Pay Your Bills](#), Consumer Financial Protection Bureau

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.

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