

Decision-Making



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BEHALF. THIS CAN BE DONE INFORMALLY OR FORMALLY.
WE DISCUSS DIFFERENT APPROACHES AND WHEN EACH
MIGHT BE APPROPRIATE.

*“A journey of a thousand miles
must start with a single step.”*

—Chinese proverb

Decision-Making

We make hundreds of decisions every day, ranging from relatively minor decisions such as what to have for lunch, to very big decisions like where we will live or work. We may take our ability to make our own decisions for granted, never even thinking about what it would be like to be unable to make life decisions or what it would be like to have the right to make our decisions taken away.

Minor children have the ability to make some decisions, and this ability usually increases as they mature. While they are minors, their parents have the legal right to make major decisions for them.

All adults are entitled to make their own decisions. Some adults may need help making some decisions, but can still make others on their own. Other adults are not able to make decisions at all. Ideally, people are responsible for as many life decisions as possible, relying on others only for those decisions too big or complex for them to handle alone.

Minor children and *some* adults with disabilities need others to make personal, financial, and/or health care decisions on their behalf. This can be done informally or formally.

Making Decisions for Others

Parents have legal authority to make decisions for their minor children (under 18 years old). They are the “natural guardians” of their minor children and have this authority without a court order or any other special documentation.

Adults are presumed to be competent to make their own decisions as to their personal well-being and their money unless a court determines that they are not competent. Sometimes, individuals with disabilities cannot make decisions for themselves so others help by making decisions for them. These decisions are often made informally. In other families, the parent’s or other family member’s authority is through a formal process, such as a trust or power of attorney.

Families, along with their attorneys, should consider all informal and formal options before considering guardianship. Legal restrictions on the decision-making ability of a person with a disability must use the “least restrictive alternative.” If none of the less-restrictive decision-making alternatives is possible, the family may pursue guardianship, which involves going to court and having a judge decide whether to give some or most of a person’s decision-making rights to someone else, who is then accountable to the judge.

Guardianship can be broad enough to cover all decisions or limited to certain kinds of decisions. It is vital to a person’s independence to obtain guardianship only if necessary and to limit the guardianship to the decisions needed. For example, a limited guardianship may give a guardian authority to make medical decisions or to make financial decisions pertaining to a person’s home while the individual continues to make other decisions.

A person does not need a guardian simply because he or she has a disability or makes mistakes or choices that others may think are unwise. If someone seeks guardianship of an adult with a disability, he or she must prove to a judge that the person cannot make responsible decisions concerning issues like food, clothing, shelter, or health care or decisions related to his or her money or property because of a disability, and that no less restrictive method is possible.

Although guardianship is available to enable others to make decisions on behalf of people with disabilities, it should be used only as a last resort, after considering all of the options. Some of the options are outlined below.

Making Personal Decisions

Advance Directives

A “health care agent” can make health care decisions on behalf of another person. A person names his or her own health care agent in an “advance directive.” Advance directives can also be used to communicate one’s wishes regarding medical treatment and other health care issues. Advance directives may include instructions to the agent regarding whether to provide, withhold or withdraw certain medical treatments, often referred to as life-sustaining treatment. Examples include artificial nutrition and hydration (tube feeding) and mechanical ventilation.

An advance directive may also be called a “health care power of attorney,” “medical power of attorney,” or “living will.” Advance directives are usually written but may be made orally, and both written and oral advance directives must be witnessed. The person signing the advance directive must be over age 18, competent to make an advance directive, and able to communicate his or her health care wishes.

A competent individual is one who is capable of making a decision about the issue presented. You are capable of making such a medical decision if you can understand the nature or the result of the treatment, are able to evaluate the risks and benefits of the treatment, and are able to communicate your decision related to the treatment.

Advance directives can be written with the assistance of an attorney or made by completing forms available from the Office of the Attorney General in Maryland. These forms are based on a sample provided in Maryland law. An attorney can draft an advance directive that is more detailed or individualized than the sample, if you want to express your wishes more fully.

An advance directive can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own health care decisions.

Surrogate Decision-Making

If an individual is not competent to execute an advance directive (and did not sign one in the past), a surrogate can make health care decisions on that person’s behalf, in certain circumstances. Maryland law stipulates who may act as surrogates. In order for a surrogate to be able to make health care decisions, two physicians must sign a certification stating that the individual is unable to make informed decisions.

A surrogate must make decisions based on the wishes of the individual, if they are known. If the wishes are not known, the surrogate must consider issues like the individual’s diagnosis, his or her wishes regarding life-sustaining treatment, and religious or moral beliefs.

According to Maryland law, the following individuals or groups, in the priority order listed, may make decisions (without going to court) about health care for a person who has been certified to be incapable of making an informed decision and who has not appointed a health care agent. A person may make a decision only if all higher priority people are unavailable or unwilling to assume that role:

1. A guardian, if one has been appointed
2. Spouse
3. An adult child of the patient
4. Parent
5. An adult brother or sister of the patient
6. A friend or relative (must demonstrate that they have maintained contact sufficient to be familiar with the patient's activities, health and personal beliefs)

Informal Arrangements

Often, family members and friends of people with disabilities step into the role of "advocate," sometimes without even realizing they are doing so. This role is typically very informal, as it requires no documents or court hearings. In spite of its informality, an advocate can have a tremendous impact on an individual with a disability and his or her quality of life. Many people with disabilities may choose who they want to advocate on their behalf.

An advocate may participate in planning meetings, help a person choose, acquire and monitor supports and services and help a person make life decisions. To be most effective, the advocate should become familiar with the resources available in the community and eligibility criteria for benefits, as well as the needs and preferences of the person with a disability.

Making Financial Decisions

Durable Power of Attorney

A competent adult can execute a durable power of attorney (DPOA) which appoints someone to act on his or her behalf to make legal and financial decisions. The DPOA must be in writing and must be witnessed and notarized. The DPOA can be broad or it can be limited so that the agent can only make certain types of decisions, such as write checks from a checking account or sell the individual's home.

A power of attorney is "durable" if it remains effective after the individual becomes incapable of making his or her own financial and legal decisions. The DPOA can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own financial decisions.

Trusts

A parent, family member, or other person can establish a trust with money or assets to benefit an individual with a disability. A "trustee" is named to manage some or all of the assets. The trustee has full authority to make all decisions regarding assets in the trust, including how to invest and spend the trust money.

Trusts can vary widely, so that they can be worded to meet your intent and the beneficiary's needs. While they provide a management tool that can eliminate the need for guardianship of the property, they have other uses as well. In particular, they are a mechanism that allows someone to leave money

and assets to another person without jeopardizing vital public financial and health care benefits. We discuss trusts in detail in a later section.

Representative Payee

If a person who receives financial benefits from the federal government, such as SSI or SSDI, needs help with depositing the checks, paying bills, and managing money, the government may appoint someone to act as “representative payee.”

A representative payee must complete some forms and have a doctor establish that the person with a disability is unable to manage his or her assets. The government will then issue the checks in the name of the representative payee and will require that the representative payee open an account into which the checks are deposited. The representative payee must spend the money only for the benefit of the person with a disability and keep accurate records of how the government benefits are spent.

Informal Options

Joint accounts offer an informal means of assisting a person with a disability in managing his or her money. If a person with a disability owns a joint bank account with another person, either owner may access the account. For example, if a father and his son with a disability are co-owners of the son’s account, the father can deposit checks, pay bills and make other decisions related to that account.

Unfortunately, joint accounts involve some drawbacks that you should consider. One drawback is that the joint owner is not required to account for how the money is spent, so there is nothing to assure that the money is used for the benefit of the individual with a disability.

Another limitation is that even though a joint owner can make financial decisions for a person with a disability, the person with a disability can make withdrawals even if he or she makes poor judgments in spending the money. Also, the joint account is counted in determining government benefit eligibility for the person with a disability.

Another type of informal arrangement is one in which a family member holds money for a person with a disability. The money may have come from a parent or from the individual with a disability. There may be some moral obligation to use the money for the individual, but there is no way to make sure the holder of the funds spends the money as intended. Even if the family member has the best intentions, the heirs or creditors of the person holding the money may claim it. This would deprive the person with a disability of his or her money with no way of getting it back.

Guardianship

The most restrictive way to assist a person with decision-making is through guardianship. A “guardian of the person” can generally make personal decisions such as where a person will live, what kinds of health care he or she will receive and where he or she will go to school or work. A “guardian of the property” determines how a person’s money is invested and spent. An individual may need a guardian of the person but not a guardian of property, or vice versa.

If a minor child’s parents die, a guardian will be needed to make personal decisions like where the child will live and go to school. This is true regardless of whether the child has a disability. If the parents’ will named someone to act as guardian of the person, that person can serve as guardian without having to go to court. The court will appoint someone to serve as guardian of the person if the parents did not name a guardian in their will.

If a child has money that should be managed and spent for his or her benefit, the court will appoint a guardian of property. This may be the same individual as the guardian of the person. If the child is at least 14 years old, he or she may tell the court who he or she wants as guardian. The guardianship of the minor will end when the child turns 18, just as if the parents were still alive.

If you have minor children, and you would like a family member or friend to serve as guardian after your death, you should name the person in your will. If the person you name accepts the responsibility, he or she will become guardian if both parents die before your child turns 18.

Because guardianship is a big responsibility, it is a good idea to discuss what it would involve and make sure that the person you choose is willing to take on the responsibility. You should consider the person's relationship with your child and his or her other responsibilities or commitments. The proposed guardian may change his or her mind or be unable to assume the responsibility as planned, so it is a good idea to name an alternate guardian, as well.

Is Guardianship Needed for an Adult?

In order to determine whether guardianship is needed for an adult with a disability, family members should ask three questions:

1. Must a decision be made related to my child's money, assets or property (guardianship of property) or must a personal decision be made related to my child (guardianship of the person)?

If no, there is no need for a guardian.

If yes, proceed to #2.

2. Is my child able to make the decision for himself or herself?

If yes, the individual should make the decision.

If no, proceed to #3.

3. Have all other options been thoroughly explored?

If no, consider all options with the goal of using the "least restrictive alternative."

If yes, proceed to guardianship.

Guardianship of the Person

A court will appoint a guardian of the person for an adult if the adult has a disability that makes him or her unable to make responsible personal decisions. Examples of personal decisions include decisions relating to safety, shelter or health care. When a court appoints a guardian of the person for an adult, he or she becomes known as the "ward." The appointment of a guardian of the person does not take away an individual's civil rights.

Sometimes, family members or friends seek guardianship so they can make health care decisions on behalf of a person with a disability. In most cases in which there is no advance directive, a health care surrogate should be able to make all medical decisions, including decisions about life-sustaining treatment, without having to become a court-appointed guardian.

If a health care decision must be made and it cannot be made any other way, guardianship may be the only option. Individuals and families may need the services of an attorney who is familiar with the Maryland Health Care Decision Act (which governs advance directives and surrogate decision making) as well as guardianship in order to make an informed choice of options.

Under Maryland law, the true guardian of the person is the court. The court appoints the guardian and delegates him or her authority to act on behalf of the individual, yet requires the guardian to obtain permission before making certain decisions. For example, the guardian must get court approval to take such steps as changing the person's type of residence or authorizing psychotropic medications.

If a medical procedure involves a "substantial risk to life," the guardian must ask the court for special permission related to the procedure. This is true whether the guardian wants the individual to have the procedure or wants to withhold the procedure. In some situations, if a close family member is the guardian, the court will give him or her the authority to make all decisions related to life-sustaining procedures when the guardianship is established. Otherwise, the guardian must make a special request to the court. A person under guardianship may still make certain day-to-day decisions, such as what to wear and who to have as friends.

Guardianship of the Property

A guardian of the property is necessary if decisions need to be made related to a person's property or money but that person cannot make those decisions due to a mental disability. A guardian of property can only make decisions about an individual's property and money, such as selling property, paying bills, or buying things. As in guardianship of the person, the court is the ultimate guardian and delegates only certain powers to the guardian of the property. The guardian must give the court an annual accounting of how he or she spent the individual's money.

Once a guardian of property is appointed, the guardian may spend the individual's funds for his or her daily support or care. The guardian may also spend the ward's funds to support people legally dependent on the ward, such as a minor child or spouse. If the guardian wants to spend the individual's money for anyone else or make gifts from the individual's money, the guardian must make a request to the court.

How to Become a Guardian

When guardianship is the last and least restrictive option, and someone wants to become guardian for a person with a disability, he or she must submit a document called a "petition" to the court. The person seeking guardianship is known as the "petitioner." Usually, the petitioner is represented by an attorney who prepares the legal documentation.

The petition must state why the petitioner is seeking guardianship, the relationship between the petitioner and the person with a disability, and what kinds of decisions the petitioner wants to make. The petition must also include written statements from two physicians which describe the person's disability.

When the court receives the petition, it appoints another attorney to represent the person with a disability. The attorney usually meets with the person, reviews all available records, talks with people involved in his or her life, and determines whether the person has the ability to make personal and/or financial decisions. The attorney should also ask the person how he or she feels about the guardianship and the proposed guardian.

The petitioner and both attorneys must attend a hearing in court. The person with a disability may attend if he or she chooses to do so. The petitioner must prove that the person is "disabled" within the meaning of the law, that the person needs a guardian, and that the petitioner is the best person to be the guardian. The judge then determines whether a guardianship is necessary, who should be guardian, and rules on other requests in the petition.

Unless there is a life-threatening emergency, it may take up to several months to set up a guardianship. It takes time to gather information to prepare the petition, interview the appropriate people and schedule the hearing. Also, it can be expensive because the attorneys representing the petitioner and the person with a disability must be paid and there are court costs for filing a petition.

The guardian must keep records of all actions taken in his or her role as guardian. After the guardianship is established, annual reports must be filed documenting a guardian of the person's decisions and how a guardian of the property has spent the individual's funds. If court permission is required to make a certain decision, the guardian must request authorization from the court and should not act until the court has issued an order authorizing the action. Sometimes, guardians rely on attorneys to help them with these reports and motions.