

Preparing for the Future

Guardianship

What is guardianship?

Guardianship is a legally recognized relationship between a competent adult and an adult with a disability (ward) who is incapable as determined by a court of law managing her affairs. In this relationship, the guardian has the duty and right to act on her behalf to make decisions which affect her life and to promote and protect her well-being.

When is guardianship necessary?

According to law, guardianship for those with developmental disabilities shall only be ordered to the extent necessitated by the person's actual mental and adaptive limitations. After she turns 18, it is important to consider guardianship because of her unique needs. If she is capable of making her own decisions, then no formal guardianship is required. If the family feels that she will need guidance in making decisions or she is incapable of making them, guardianship should be considered. It is a very difficult decision, because her rights are taken away. However, the family has to ask the very simple question, "If she cannot make decisions, who will?" While you may trust your local or state case manager, do you trust them enough to carry out this heavy responsibility? When you consider the fact that there is a high turnover in this case management area and your favorite social worker may leave, you may want to provide that personal support yourself.

Who should the guardian be?

Parents can be guardians once the child turns 18. In fact, many parents carry out this role without the formal legal guardianship by the simple fact that the person continues to live at home and most agencies respect the parents' informal position as advocate (someone who assists the person without the legal authority to make decisions). It is only when someone or an agency refuses to recognize the parents' decision that things can get complicated. For example, your daughter may need surgery and the hospital will only accept her signature for consent. The hospital attorneys may simply refuse to accept her signature because they do not believe she can give "informed consent", so everyone is stuck in limbo. Legal guardianship can avoid this problem because the parents can act on her behalf. While we usually speak about the parents acting in this role, any sibling or relative can do so. Even good friends can serve as guardians.

Is the guardian responsible for the ward's care?

Yes, the guardian is responsible. The courts or an appointed social service agency will/should check on the person on a regular basis. This is not always done, however. If the case manager suspects any abuse or neglect, he must report it. The guardian could lose custody. There are laws in place to protect the person. However, the bureaucracy doesn't always keep up. Therefore, it is essential for families to recommend people they trust.

Is the guardian financially responsible for the cost of the ward's care?

No. Generally, the guardian does not assume financial liability for his charge. Therefore, it is essential that you set up a trust or other account so there will always be funds available for your daughter.

The guardian is not legally responsible for any debts incurred by the person. However, if the guardian incurs the debts, he or she is responsible. If the person charges a TV on a credit card, the guardian does not have to pay. If the guardian charges a TV for the person, then the guardian must pay. Without this safeguard, few people would take on guardianship. They would be sued for things the person did.

How do we go about establishing guardianship?

Depending on your state, the process can be easy or extremely difficult. The first thing you must do is consult an experienced attorney. Find someone who does guardianships on a regular basis. The attorney will file a motion with the local court. The court will appoint an attorney who will act on behalf of your daughter. Generally, the court will send an investigator to meet with you. In some states, the local or state agency will also conduct an investigation. Everyone goes to court on the appointed day, at which time the judge will review the reports and ask questions. Again, it depends on the state, but many of these guardianship hearings are held in smaller courts or even in the personal chambers of the judge.

Are there different types of guardianship?

The types of guardianship which should be considered are:

- Full - All rights are taken away and given to the guardian.
- Limited - no rights are taken away; however, the courts may give certain responsibilities to the guardian, i.e., sign contracts, handle finances, make housing decisions, etc. Approximately 30 states recognize limited guardianship.
- Co-guardians and back-ups. It is always a good idea to obtain a co-guardian or a back-up. For instance, the court may appoint the mother as the primary guardian. The father would be appointed as the co-guardian to act with the mother or as a back up if anything happened to the mother, such as illness or death. Many states permit the guardianship papers to include successor guardians. In a situation where an elderly mother is the guardian and she has to go into a nursing home, the court could approve the siblings as successor guardians at the same time they approve the mother's guardianship. In this way, the minute the mother goes into a nursing home or dies, the siblings have legal authority to take over.

How can we make sure she is cared for if we die?

Guardianship is important, but it does not replace a good, well-written life plan and letter of intent. Parents need to put in writing what they would like for the future. This document, which is not legally binding, is called a letter of intent. It gives future caregivers insight into how your daughter should be provided for in the future. Unlike a detached analytical report written by a case worker, the letter of intent is a warm personal document which gives information on how to provide the best possible care. This letter of intent combined with a life plan or strategy for providing guardians, advocates, housing, etc. will be the difference between basic care in an institutional setting and a warm, loving lifestyle. Comprehensive planning will assure that adequate funds will be in place if you die first.

Who can handle these matters?

The team should include an estate planner, an attorney and a CPA. Look for an estate planning team that is experienced with special needs families. They should have a good working knowledge of government benefit programs and the service delivery system for the disabled from birth to death. The team must take the necessary time and feel comfortable working with special needs families. The National Institute on Life Planning, dedicated to serving the needs of disabled persons, recommends the following approach to developing a Life Plan:

Decide what you and your loved one wants - the person with the disability is the key member in the decision making process. It is her life. Look at all areas - housing, employment, medical care, etc.

Put your desires in writing. Prepare a Letter of Intent which will let future care providers know what you want for the future.

Decide on an Advocate or Guardian - someone who will look after, fight for and be a friend.

Determine the cost of your Life Plan and find the resources.

Do the necessary legal work which might include Last Wills and Testaments, Special Needs Trusts, Durable Powers of Attorney, etc. - Consult a qualified attorney for this specialized work.

Develop a good record keeping system to keep all of your materials in one place. When there is an emergency (like your death or nursing care), people need to find this information quickly. Let others know where you keep your records.

Review and update your Life Plan at least once a year. Keep it current.

One way to provide for the long-term needs of our kids without putting their SSI resources at risk is to establish a "special needs trust." Any assets of the child and any gifts or bequests they might receive need to be redirected into the trust, which then "owns" them instead of the child. The trustees of the trust make the decisions about how and when to spend any of the money, but it does not get in the way of any of the governmental services the child is entitled to. Trust money can be used for clothing, outings, vacations, etc. at the discretion of the trustee(s). The trust will get its own tax ID number, and will have to file a separate return with the IRS each year. This is a fairly specialized type of trust and you might want to seek out someone who has specific knowledge about special needs trusts to guide you in setting one up. One potential hazard is inheritances that the benefactor leaves to the child, rather than the trust from state to state.

Social Security

When your daughter reaches her 18th birthday, she becomes eligible for Supplemental Security Income (SSI) automatically.

There is no financial formula, and the parents' income is not counted. She can probably qualify for the highest amount of benefits.

It is best to apply a month or so before she turns 18 so that her benefits will not have to be retroactive. If you do not apply, she does not receive the benefits.

These funds are to be used to pay for her lodging, food, clothing, recreation and other needs. The Social Security Administration uses a mathematical formula to calculate her benefits.

If she lives at home, you should assign an amount for her to pay "rent" to access the higher benefits. If she lives away from home, her SSI check is sent to her residential placement to help pay for her needs.

You should expect a 6 month wait for the bureaucracy to get all the paperwork approved. They will still backdate payments.

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