



## **GUARDIANSHIP/CONSERVATORSHIP: PROTECTING YOUR ADULT CHILD WITH MPS OR RELATED DISEASE**

**Laurie Turner, National MPS Society**

Parents are meant to care for and protect their children. This care begins at birth and continues for many years. For families who have a child with MPS or related diseases, this care often extends past the age of maturity, 18 in most states, 19 or 21 in some states. In many cases, your child may be considered an adult, but what happens if they are not able to make adult decisions? The law states that the child is an adult, and as a parent you are no longer allowed to care for their money, gain access to health information, or even make necessary medical decisions. This is why many families consider guardianship and conservatorship.

In some states, a court appointed legal guardian of an adult automatically has the power of a conservator. In other states, it is necessary to get two appointments from the court system, one for guardianship and the other for conservatorship.

Guardianship and Conservatorship are the legal rights given to one person to protect and manage the personal care, finances, or both, of another person. The person needing the help is called the ward or conservatee, and the person providing the help is called the guardian and or conservator. A judge makes the determination that the ward or conservatee is unable to make independent decisions.

You may feel more comfortable obtaining legal advice to establish guardianship and or conservatorship, however, most states make it easy to do. Laws and terms can vary from state to state: in some states, a guardian is only used to reference personal care, and a conservatorship is limited to finances. It is important to know the laws and terminology of your state.

### **Who can serve as a guardian and conservator?**

Often a parent is the best option, or another close relative or friend. Conservatorship is a significant responsibility, and it is important to name a person who is willing and able to assist the ward or conservatee. Siblings are often a good choice, however, they should be geographically close, and not over extended with their own personal responsibilities. It is not a good idea to pressure anyone to become the conservator if they are unsure of the responsibilities. Two people can share the responsibility, with one appointed to handle the care of the personal needs, and one to handle the care of the financial needs. A bank or other financial institution can also serve, either independently or jointly, with a family member or friend who needs financial expertise.

### **When do we need to start to think about it?**

It is important to start thinking about this early and also to plan ahead for the future. As parents of special needs children, it is especially important that you have a will in place. You can name a guardian or conservator in your will. It is recommended that parents begin planning for the guardianship / conservatorship process when their child is 15 or 16, to allow for plenty of time to make arrangement before the age of maturity.

The process has several involved steps that require advance planning:

- The would-be guardian or conservator must read a handbook which outlines all of the duties and liabilities of the position.
- The conservator must sign an oath stating that he/she will perform the duties according to the law.
- All papers must be filed with the court.
- If the judge approves and appoints the conservator, letters of conservatorship must be obtained from the court clerk; this spells out the specific powers which the judge has authorized.

Certified copies must be kept and shown to provide proof of the guardian and conservator's authority to act.

### **What is included in the powers and duties of the guardianship and conservatorship?**

Individual circumstances vary and will affect the level of conservatorship. The judge involved will help determine what is needed for the ward or conservatee.

Some examples of the Guardianship for personal care include, but are not limited to:

- Deciding where the ward or conservatee will live
- Arranging for meals, transportation, clothing
- Personal care
- Recreation and medical therapies
- Health care

Some examples of a Conservator's role of financial care include, but are not limited to:

- Making a budget
- Paying bills
- Investing money
- Collecting income
- Protecting assets

A judge can determine how much responsibility the ward or conservatee can maintain. Some individuals may be able to personally care for themselves, however, they may need assistance with their financial or medical matters.

### **How do we decide if this is the best option for our family?**

A guardianship is important for medical management purposes. If your child is not able to communicate effectively, a guardianship is the only way to protect them and the only way to insure you, as a parent will have access to medical information, which would otherwise be considered private.

In setting up a conservatorship, a family will turn power over to the court system. If you have a special needs trust and or other type of financial planning established, a conservatorship may not be necessary. Temporary conservatorship can be created if a person needs immediate help. This could arise if the parent dies or becomes incapacitated without having planned for the care of their child with special needs. It may be difficult for family and or friends to arrange this on short notice, and the court may simply appoint someone to assume the responsibility.

If an adult with special needs is receiving government benefits, such as SSI or Medicaid, and has no other assets, a conservatorship may not be necessary. If gifts are given to the child, they can be placed in a special needs trust which can be created to pay for items and services above and beyond the minimum necessities that the government provides. Court supervision may not be needed for a special needs trust, however, you will need to verify the laws in your state.

For further information, please contact a financial advisor, or lawyer who specializes in guardianship and conservatorship or contact your state's health and social services department or your state's probate or family court system. Many or most of the application forms you will need to complete are available online in your state.

In many states a third party (another family member, friend) can apply and be granted a Special Advocate. This person can make decisions when the guardian is not available or out of town. The Special Advocate can be appointed at the same time you apply for guardianship or conservatorship. The Special Advocate is allowed to make medical decisions in the absence of the guardian, but is not able to step in and fill the conservator's role.

After being appointed a guardianship/conservatorship, annual reports are due to the family court, and again most of these forms are available through your state. Reviews of your appointments are done anywhere between 1 and 3 years for the duration.

Although this may seem like a big undertaking, this role is vital and will give you peace of mind knowing you can still make all the important decisions for your loved one.