GUARDIANSHIP AND DEVELOPMENTALLY DISABLED INDIVIDUALS

Introduction

When a child with disabilities reaches the age of majority adulthood (which in most cases is the age of 18, but may vary from state to state), it may be time for the child’s parents to consider guardianship – they do not automatically remain their child’s natural guardian. It is a decision that should not be taken lightly – in many states it means that the individual, deemed to be incapacitated, loses all civil rights, including the right to vote, drive, or marry. Guardianship is a judicial determination made in a court of law after an investigation in which the alleged incompetent person may be represented by legal counsel. Because the process of appointment of a guardian varies by state, the services of an attorney are often required.

When Is Guardianship Needed?

All adults with severe disabilities do not require a guardian. Guardianship is only an avenue to pursue if the person’s parents, doctor, psychologist, and caregivers (such as teachers) all agree that the individual is incapable of making informed decisions with appropriate guidance and information.

Parents often think that because their child cannot balance a checkbook, their child needs a guardian. In today’s world, guardianship for people with disabilities has little to do with the capacity to handle finances. There are other mechanisms for dealing with financial matters, such as powers of attorney, representative payees for government benefits, and trusts.

Understanding Guardianship

Guardianship is considered with informed decisions about where a person should live, what care and supervision is required, and how to interact with the medical community. These areas of concern require that the guardian be informed of the services available to their ward within the community and how to access them.

Some states offer limited guardianship, in which the guardian is limited in the scope of decision-making. For example, the guardian may have the right to make decisions on medical issues, but not on decisions regarding where a person will live.

The role of the guardian is to enhance the ward’s lifestyle while including the ward in the decision-making process as much as possible. The guardian is expected to determine the ward’s wishes and goals and to advocate on the ward’s behalf. Guardians must not view their role as a means of limiting activity. For instance, few courts would give a guardian control over social interactions of their ward.

Parents also have to consider who will be their adult child’s guardian after they have passed away. It is most helpful to choose an individual who is of the child’s generation, perhaps a sibling or a friend of the family. In some states, there are not-for-profit organizations that provide guardianship services.

In many states, parents can designate a substitute guardian (the next guardian) when they cease to be their child’s guardian or they may name someone in their wills.

For additional information about the state procedures and local services, contact the local Area Agency on Aging, the Cerebral Palsy Association, Muscular Dystrophy Association or Head Injury Association.