

GUARDIANSHIPS FOR FAMILY MEMBERS WITH DISABILITIES

It is no secret that family members who care for an individual with a disability face a unique set of challenges. If the disability is severe enough, assisting a family member with a disability involves having input into that person's day-to-day living and health care decisions. However, for parents of children with disabilities, the legal landscape drastically changes when their child turns age nineteen (19). This is because, at age 19, a child legally becomes an adult under Alabama law, and then the child is free to make his or her own decisions. Conversely, the adult child's parents no longer have a legal obligation to support their child, and are no longer required to be consulted about decisions concerning their child's welfare, ***even if the child does not have the ability to make informed decisions.*** Unless the child's ability to make decisions is brought into question, the law assumes that an adult is perfectly capable of handling his or her own affairs.

Federal patient confidentiality laws have become increasingly strict about what information (if any) a doctor or other health care professional can share with someone who is not the patient. Because of this, parents are often routinely excluded from conversations involving their adult child's medical treatment or care. If that child is unable to make informed medical decisions on his or her own behalf, this poses a very serious concern. When the parents are left out, an adult child with a disability often has no one who is able to assist him or her in these important treatment decisions.

We are often asked whether parents of an adult child with a disability need to be appointed as their child's legal Guardian. Our response used to be, "not unless you are having a problem communicating with medical care providers for your child." However, in light of the situations we continue to see caused by new patient confidentiality laws, we now maintain that being appointed as your child's legal Guardian can be particularly helpful to avoid any lapse in communication with health care professionals.

In Alabama, the roles of caring for a person in need of protection have been separated into two parts: a Guardian and a Conservator. A Guardian is in charge of the care of the ***person***, meaning that the Guardian is in charge of making decisions about where an individual will live, day-to-day living decisions, and medical/health care decisions. By contrast, a Conservator is in charge of an individual's ***property***, meaning that the Conservator is in charge of handling an individual's finances when they are not able to

do so for themselves. Guardians and Conservators are appointed by the Probate Court.

Not long ago parents usually expected to outlive their children with developmental disabilities, especially those with disabilities that commonly have physical impairments as well. In today's world of improved health care, that is no longer the case. Individuals with Down Syndrome are regularly living into their 60's now, whereas only a decade ago, 35 to 40 was considered a maximum life expectancy.

Even if a parent has never had a problem communicating with a health care provider about his or her child, and there is no need for a formal Guardianship of the child during the parent's lifetime, ***there will be an immediate need for a Guardian to be appointed at the parent's death.*** It is critical that a parent of a child with a developmental disability have in place a Will that nominates a Guardian for the child at the parent's death.

Sometimes this day comes even sooner if the parent develops dementia or becomes unable to accompany the child to medical appointments. Once this situation develops, it is important to have a Guardian appointed as soon as reasonably possible. While a hospital is required to provide emergency care for the individual, the same is not true for routine care for a chronic illness, such as allergies, diabetes, infections or other common health problems of adults with disabilities. Thus, the parent should also have in place a Durable Power of Attorney that contains a nomination of a Guardian for his or her adult child should the parent no longer be able to care for the child. While the Probate Court is still required to appoint a Guardian *ad litem* and a Court Representative to make sure the nomination is appropriate and in the child's best interest, the written instruction of the parent carries priority for the Court's decision. A sibling of the child with a disability often becomes the legal Guardian, even before the parent passes away.

When it comes to providing assistance for an adult with special needs, being proactive rather than reactive pays benefits. Consider becoming your adult child's legal Guardian to avoid any chance that your child's health concerns would not be made known to you.

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