Summer 2022

Estate Planning Update Summer 2022 - Guardianship and Alternatives for Adult Children

For those of us raising a child with an intellectual disability or developmental delay (ID/DD) or a mental health impairment, there are many decisions and changes to contemplate as our children reach the age of majority. These decisions include those involving transition planning within the special education system, converting to adult support services, applying for government benefits and contemplating whether our loved one has the capacity to make independent legal choices. There are many different fiduciary roles designed to assist our adult children with decision making, including guardians and conservators appointed by the court and agents appointed by the individual or by a government entity providing services to such individual. It is important to understand which role is appropriate and who has the authority to make a particular decision.

Guardian and Conservator

All individuals are presumed to be legally competent with the right to make their own decisions once they reach the age of majority in their state (typically age 18). These rights include the right to make financial decisions and enter into legal contracts, the right to make their own medical decisions and the right to keep their medical information confidential. If an individual is unable to make informed decisions due to a disability, a local probate court will appoint a legal guardian who is tasked with making educational, financial and medical decisions for the incapacitated person. The guardianship may be limited by the court so the incapacitated person retains the right to make certain decisions. The court will typically require the opinion of a medical professional as to the individual's lack of capacity to make informed decisions. In some states, there are separate appointments for a guardian of the person to make educational, medical and life decisions, and a conservator or guardian of the estate to make financial and legal decisions. The court may appoint the same person to both such roles. Guardians and conservators are subject to ongoing court oversight.

Representative Payee

If an individual is receiving either Supplemental Security Income benefits or Social Security disability income from the Social Security Administration (SSA) and that person does not have the capacity to manage such income, the SSA will appoint a relative, a friend or even an agency to be the "representative payee." The role of the representative payee is to use such income to meet the beneficiary's basic needs for food, shelter and medical care as well as personal needs, including those for clothing, therapies and recreation.

Trust

It is vitally important that an individual with special needs receive any inheritance or substantial gift in trust. A Special Needs Trust (SNT) would typically be used in such a case. An SNT is designed to hold that inheritance or gift for the benefit of the individual while preserving the individual's eligibility for means-tested government benefits. The trustee manages and invests the trust's assets on behalf of the individual, making distributions that are in the best interests of the beneficiary, taking into account the impact such distributions may have on any government benefits. The trust should protect the individual from exploitation, financial waste and financial mismanagement. The trustee is named in the trust document by the creator of the

trust (typically parents or relatives of the individual). The trustee typically is not under the supervision of a court. An SNT designed to receive a gift or inheritance is a third-party trust created by individuals other than the disabled individual and is distinct from a self-settled SNT, which is typically created by family members or a court to hold assets already owned by the disabled individual.

Supported Decision Making

There is a common misconception that all individuals with ID/DD require a court-appointed guardian to make all decisions for them for the duration of their lifetime. Families of children with ID/DD who are approaching adulthood typically receive only information related to the court process of guardianship. These families often receive neither information offering alternatives to court-appointed guardianship nor access to other resources, such as a formal support network that could encourage the adult child's independent growth.

Statutory alternatives to the court process could permit adults with ID/DD to retain independent decision making, self-advocacy, self-expression and the ability to select individuals to assist them. Many people informally engage in supported decision making when asking the opinion of others, such as asking a friend who is a mechanic to advise on the purchase of a car or asking a friend who is an interior decorator which paint color looks best for a bedroom wall. Adult children with ID/DD are better served by formally identifying the individuals who will assist them in a "supported decision-making agreement." Supported decision making is gaining leverage nationwide, and disability organizations and advocacy groups, such as the Arc and the National Council on Disability, strongly support the use of these agreements as an alternative to court-appointed guardianship. Some states, such as Rhode Island, have passed laws to recognize these agreements as legally enforceable contracts. In states where such laws do not yet exist, other documents remain viable for promoting supported decision making, provided that the adult child with ID/DD who retains the requisite level of capacity does not subsequently revoke them. Documents that serve as alternatives (or supplements) to supported decision-making agreements include the following:

Health Care Proxy/Health Care Representative

A health care proxy is a document that names one or more individuals as having the authority to make medical decisions for a person unable to do so independently. Typically, a health care proxy assumes full responsibility for the medical treatment and care of an adult with ID/DD, but when able to do so, the adult with ID/DD could assist with more routine care decisions.

Durable Power of Attorney

A durable power of attorney allows one or more individuals to assist with personal and financial affairs, including banking, legal matters and applying for government benefits. (The SSA requires individuals to sign their own form designating a representative.)

Educational Agent

Adult children with ID/DD may select an educational agent to represent them regarding individualized education programs and other educational needs. The educational agent will advocate for and provide approval of special education services, promoting continuity and minimizing exploitation within the educational system.

Conclusion

Every individual has the right to dignity, respect and self-determination. Regardless of whether an adult with ID/DD has a legal guardian or employs alternatives, such as the supported decision-making agreement, to designate supporters, those tasked with such responsibility have the duty to consider the disabled person's wishes, desires and preferences. Promoting independence and self-determination in the decision-making process is paramount and understanding the disabled person's desires is imperative.

Day Pitney Estate Planning Update - Summer 2022 (pdf)