

Parents of special needs children should develop plan for later in life

By Denice Gierach – As published in the Naperville Sun – April 29, 2007

If you have a child with special needs, you understandably worry about taking care of their needs while you are alive, but also after you have died. A disabled or special needs parent needs to find appropriate care and services, work with the child to obtain independent living skills to the extent possible and protect that child from any harm. This type of planning involves managing finances and making personal decisions in the event of the disability or death of both parents. A disabled child may need the parent to make decisions for that child well into adulthood and need to look forward to future residential needs, as well as finding the appropriate caretaker for that child when they are unable to do so.



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First, one should note that without appropriate estate planning, the disabled or special needs child will inherit from the parents. Since the child is not able to manage the financial assets, this would most probably require the court appointment of a guardian. Such a guardian would have to request for distributions to be made for the benefit of the child and account to the court each year. In addition, if the child inherits from the parents, the assets that the child is entitled to receive may preclude the child from obtaining certain types of governmental assistance benefits without the assets being spent for their benefit prior to applying for governmental aid programs.

The area of governmental benefit programs is complex, as the child may be entitled to one or more programs and the requirements are different for each type of program. For instance, unearned income and ownership of assets do not affect eligibility for Social Security and Medicare benefits (when the child is an older adult), but they do for Supplemental Security Income (SSI) and Medicaid. SSI eligibility is affected not only by cash and checks paid to a child but also by in-kind income in the form of goods and services purchased by third parties. The goal is to insure that the child is not disqualified from receiving assets placed in the child's name at the parents' death or disability.

Many parents make use of a discretionary special needs trust. This trust document is established and funded by the parents and must clearly state that the purpose of the trust is to supplement, not to replace, funds available from governmental and other benefit programs. The trustee must have complete discretion to use the funds in any way for the beneficiary. In addition, the child must not have any legal right to access the assets of the trust or the income of the trust. The trustee chosen must understand the rules concerning the governmental programs, so as to not make a distribution that will adversely impact the child's eligibility to obtain governmental assistance.

It may also be advisable to obtain a comprehensive professional evaluation of the child's physical, medical, social, emotional, education and services needs, if one has not yet been done. This will assist your attorney and financial advisor to refer you to the appropriate case manager or agencies that service children with the particular disability that the child has that will be the most beneficial to the child.

Caring for a disabled child or one with special needs is a 24/7 job. If you are no longer around to do this job, you should plan ahead to make sure that your child will obtain proper care and be able to live a life that will be the best under the circumstances.

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