



special focus | planning ahead

Protected Tomorrows: Start by planning today

by Mary Anne Ehlers

Overwhelmed is the prevailing word used by parents with a child who has special needs. There are so many things that need to be taken into consideration on a daily basis, compared to their other family members. So, when it comes to planning for the future, many parents don't know where to start.

The sooner parents begin a plan of action, the better. It will ensure key decisions are made at the appropriate times so their child reaches their fullest potential.

Parents should first think about two areas that go hand in hand: legal options and financial planning (specifically a special needs trust and government benefits).

Special needs trust

As a parent, you need to start with a solid estate plan that includes a special needs trust. This special type of trust is a way for parents to put money aside without jeopardizing government benefits. It is a vehicle that holds assets, which can be used for supplemental care for your child. It answers the question of who is in charge and if there are limits to how the money for your child is used. Seek an experienced attorney who specializes in this type of trust. But, before meeting with an attorney, make some decisions with a qualified special needs future care planner—a professional who can provide objective guidance, knowledge and, most importantly, empathy to your family.

Decide when to create it. You can create a special needs trust so it's activated either at death or while you're still living. A "testamentary trust" takes effect upon your death, but its disadvantage is certain laws change; the trust could be negatively affected. Having a stand-alone trust now



has a couple of advantages: it offers flexibility to change the trust through a "trust amendment," or "grandfathered" rights, if the law changes. Setting up a trust as a stand-alone trust also allows friends and family to refer to the trust for such things as gifts or inheritances.

Decide what type of trust. The 3rd party special needs trust that will likely provide the most flexibility throughout your child's life is the "revocable trust" with an "irrevocability trigger provision," when certain change occurs such as death or divorce. However, more common, since the 3rd party trust may be funded during your lifetime, you should consider having an irrevocable trust created, but make sure that it allows it to be amended to stay compliant with the law. You should also familiarize yourself with the "payback trust," which is usually reserved for cases when money is incorrectly left in the name of the child with special needs. Also referred to as the "CERA 99 trust," its purpose is to place assets owned by the person with the disability into the trust to be spent on supplemental care during the life of the child with special needs; however, when the child passes away, the remaining money in the trust is first used to reimburse the state for benefits paid during the child's lifetime before it's distributed to the remaining designated heirs.

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Decide who will be the trustee(s) and future caregivers. These are difficult decisions for many parents, and ones that should not be taken lightly. You will need to consider who you will want to handle the day-to-day living responsibilities (caregivers) and money matters (trustee) for your child. And, who is willing to learn what is involved in making daily decisions for your child. Ask potential caregivers to take the child for the weekend and see how they manage. Also, consider if the future guardian and trustee should be the same person.

Decide how to fund the trust. Any asset—including proceeds from life insurance policies that you have for the benefit of your child—should be titled under the trust. There are three primary ways that a trust can be funded: inheritances, savings on the child's behalf and child support. It is very important that you remember to change the beneficiary of your retirement, annuity, IRA and life insurance accounts to the child's special needs trust. If not, you'll likely be forced to set up a less than desirable pay-back trust. But, turn to a financial professional before you take action so you are aware of certain tax consequences. Also, decide the percentage of money to go to the trust versus your other able-bodied children. Remember, the special needs trust is a tool in the special needs planning process that provides for care above and beyond living needs and allows you to maximize your child's resources.

Remember, the special needs trust is a tool in the special needs planning process that provides for care above and beyond the basic living needs and allows you to maximize the benefits that your child receives.

Government Benefits

As your child's needs evolve throughout their life, you have to consider such things as medical expenses, early intervention and various programs.

Your child's biggest resource for funding may be government assistance programs, which can be confusing to access. An advisor who specializes in special needs planning can provide information about the proof you will need to show your child is disabled, the questions government officials will ask and the actual visit to the social security office. This right planner also can act as your representative through this benefits application process.

Here are a few things you need to know about government benefits and other programs to access for your child.

Entitlements. Social Security Disability (SSDI)/Social Security Administration (SSA) and Medicare are benefits

most Americans get because they bought into it throughout their working years. Your special needs child benefits from your contributions. It is important that you always save your social security statements for review. They tell you a lot about not only your own benefits, but also what your family receives when you retire and/or die. SSDI/SSA provides cash to meet daily living expenses and to supplement any other benefits, while Medicare assists with medical needs. Medicare does not pay for prescriptions unless you have Medicare Part D.

Needs-based benefits. Supplemental Security Income (SSI) and Medicaid go hand in hand and will only help your child after a review of your income level and assets (or your child's income and assets once they reach the age of 18). Eligibility requirements need to be met to qualify. SSI provides cash to meet daily living expenses. With Medicaid, you can have health insurance; it simply pays for deductibles and co-pays that your health insurance does not cover. But the most beneficial reason for your child to qualify for Medicaid is to gain access to funding which will provide for your child's programs, workshops and residential housing.

Local benefits. It's also important to know if your advisor is involved with special needs organizations, and informed about the issues that you, as a parent, and your child face. In addition to serving as your advocate, so you can give your child more personal attention, these special needs planners connect you to non-financial programs, support groups, recreational opportunities and many other resources your family might benefit from in your state. A planner also keeps up with law changes and new programs, so you don't have to navigate the system. A knowledgeable special needs planner and an experienced estate attorney are invaluable assets to your family as you plan the future for your child with special needs. By working with a team of these specialized professionals today, the dreams for your child with special needs will be closer to a reality tomorrow.

Mary Anne Ehlers is founder and president of Protected Tomorrows, the leader in enhancing the lives of families with individuals who have special needs. Assisting parents in planning the future for their child with special needs (planning ahead) is a key to helping other families do the same for their loved one. In addition to one-on-one consultations, Protected Tomorrows offers an Online Future Care Planning System, which addresses legal options and government benefits. For more information on the online system or special needs future care planning, visit www.protectedtomorrows.com.

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