Making Sense of Special Needs Planning

By Protected Tomorrows, Inc.

If you are a parent of a child with special needs, government benefits and legal options are often confusing. We often hear families say that their family member is not eligible for benefits, or that everyone is turned down the first time they apply. We also hear that in order for a person with a disability to receive benefits, the parents must disinherit the child in their will. Both of these statements are not true.

Here is a brief explanation of government benefits that your child may or may not become eligible for, but you may want to investigate:

- **SSI – Supplemental Security Income** – A federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind and disabled who have little or no income. It currently provides a maximum of $698 per month to be used for basic needs such as food, clothing and shelter. This amount will increase to $710 per month in 2013. It is generally for people who have little or no work history. An SSI applicant must limit their assets in order to qualify for this benefit. Basically, the allowable assets for a person applying for SSI are a home, one car, a pre-paid funeral, and $2,000. Of course, understanding what is considered an asset is important, as well as which is the appropriate asset for your family member to own.

- **SSDI – Social Security Disability Insurance** – A federal cash benefit program that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual’s family if you are “insured” meaning that you worked long enough and paid Social Security taxes. Each insured individual should receive a statement from Social Security explaining their status of eligibility. Social Security statements can also be obtained from http://www.ssa.gov/mystatement/.

- **Medicare** – A federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.

- **Medicaid** – A state run medical assistance program for
certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the Federal government establishes general guidelines for the program, the Medicaid program eligibility requirements are actually established by each State. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs. This program has asset limitations similar to the SSI limitations.

When planning for your family member, it is important to build a life plan. This involves understanding your dreams for your child’s future, and recognizing the fears you have for them as well. The next step is to identify how those dreams can be built upon and the fears can be mitigated as you build a future plan for your child.

It’s important to evaluate your child’s entire picture and take a few more things into consideration:

- Although you may be dealing with a child at this time, what do you see for him/her in the future? Supported employment? Workshop employment? Residential living?
- Does your existing health insurance remain in effect when your child turns 26?
- What assets are presently in his or her name? Example: savings bonds, life insurance, stocks, mutual funds, homes, etc.
- Is there a possibility of inheriting any money or assets?

Once you’ve answered these questions, you can then look at what benefits he/she may be eligible to receive and how to best position his/her assets and income.

Often parents ask, is there a way I can leave an inheritance to my child with disabilities without negatively impacting my child’s benefits? YES. An individual may set up a Special Needs Trust that will permit this. The following are the most common types of Special Needs Trusts:

**Third Party Discretionary Supplemental Needs Trust** – A trust than can hold cash, personal property, or real property, or can be the beneficiary of life insurance proceeds. Simply stated, other people’s money or property that they choose to contribute or leave to the child with disabilities can be set aside safely to provide for the supplemental care for your child’s future.

There are some very specific rules for this type of trust, such as that it must be irrevocable, the funds must be used for supplemental care only,
and that the assets of the trust cannot be made payable directly TO the individual with a disability.

**First Party Discretionary Supplemental Care Trust or Payback Trust** – A trust that can hold cash, personal property or real property that is owned by the person with disabilities. This can only be set up by parents, grandparents, or legal guardians of the person with disabilities, or the court. This trust also has very specific rules that must be followed, and it differs from the Third Party trust in that it must have a payback provision, so that the state is paid back for medical expenses paid, at the death of the beneficiary.

***When thinking about trusts, it is imperative that you speak with an attorney who has extensive experience and knowledge in the Special Needs Trust arena.***

Another area to be discussed is the area of future guardians, or Future Care People™ as we call them. Who will be there to step into your shoes if something were to happen to you? Who will handle the medical, school, employment, residential, and recreation decisions? Many parents postpone the planning process, as they find this decision so difficult. However, it is one of the most important areas to document.

Last but not least, one step that we find very important is to document your child’s life. Think of all of the things you have filed away in your head that are specific to your child – all things from the very small minute details to those things that may be very complex. Who else knows what you know? If something should happen to you, who will have the “instruction book” of care?

Would they know never to try a certain medication, or would they know a certain shampoo gives your child a horrible rash even though it smells so good? Would they know your child’s everyday routines that may seem inconsequential, but are of major important to your child’s every day functioning? Pass this information along in some written form. Keep a journal, a notebook, or whatever works for you. While this task may appear to be just one more thing to do, in the long run, it’s well worth the effort.

To many families these issues are often confusing and just plain daunting. The important thing is to be patient and do your homework so that you are better prepared for the future.

Can you do this yourself? Of course! There are many resources available on the Internet, such as: www.protectedtomorrows.com, www.ssa.gov, and www.statehealthfacts.org among many others. Additionally, Protected Tomorrows has a cost effective program to provide families with tools and
resources for planning for their loved ones’ future. The Protected Tomorrows Family Membership offers webinars covering many of the topics discussed in this article, exclusive access to extensive resources, as well as an interactive planning tool to guide you through the Process for Protected Tomorrows – a holistic, step-by-step approach to creating a Future Care Plan™ for your loved one with special needs. Go to www.ProtectedTomorrows.com for more information.

Protected Tomorrows, Inc. is the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. Through their work with clients and the family’s advisors, and alongside other advocates and legislators, Protected Tomorrows addresses many concerns of families with special needs such as: future care funding, government benefits, legal considerations, residential options, employment opportunities, recreational choices, education options and family communication. For questions, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com.