

# While the Science is Still Uncertain, the Need to Plan for Your Child's Future is a Sure Thing!

By Bernard A. Krooks, Esq and Sheryl R. Frishman, Esq  
Littman Krooks, LLP

When a parent is given a diagnosis for their child of Autism or Pervasive Developmental Disorder (PDD), they are bombarded with a variety of medical, therapeutic, educational, and holistic treatment methodologies that promise to "cure" Autism. This leaves parents in the position of believing that their child's developmental issues may be resolved and may not require a lifetime of care. Even though these treatments are available and may be extremely effective, they do not alleviate the necessity for parents to take the steps to plan for the future of their child. Often in our practice, parents of children with Autism and PDD are reluctant to plan, because they are still waiting to see what the outcome will be of the therapies and interventions. While understandable, waiting is a mistake. If a plan is not put in place, you are hurting your child, the person whom you are trying so desperately to help.

The thought of you predeceasing your child is frightening. It is so frightening that you may do everything you can to try not to think about it. Who wants to

needs child. Once you write the letter, sign and date it. Each year, you take it out and add to it (or revise it if it is on the computer) and sign and date the changes.

## Last Will and Testament

A Last Will and Testament is a legal document that provides instructions on how you want your assets distributed at your death. Why is it so important to direct how assets are to be distributed? When your special needs child is no longer eligible for services from their local school district, the primary way to receive the necessary, therapeutic, residential, vocational, and educational services they require is through means tested public benefits. These benefits, (for example, SSI, Medicaid, etc.) not only require a determination of disability in order to be eligible, but an applicant must meet stringent income and resource levels. This means that if your child has more than, or inherits more than, the applicable income and resource levels they would not be eligible for public benefits. These benefits are typically the lifeline or services once your child's school program is done. A Last Will and Testament is important tool since it would ensure that your child with special needs would not inherit your assets directly, which may put them over the applicable public benefits levels.

## Supplemental Needs Trust

While public benefits cover many



**Bernard A. Krooks, Esq**

face their own mortality? Who wants to face it, especially when you are so busy bringing your child from therapy to therapy and hoping for a successful outcome? Nevertheless, there will most likely be a time when you will predecease your child and it is essential that you put a plan in place to ensure that

services your child may require as an adult, they do not cover everything. Additionally, most parents are not pleased with the fact that they have to disinherit their special needs child in order for their child to access public benefits. Fortunately, there is a very important tool that loved ones can use to allow a child to remain eligible for public benefits, but also have the "extras" that you would want them to have. This important tool is the Supplemental Needs Trust, also sometimes referred to as a Special Needs Trust. A Supplemental Needs Trust holds assets for the benefit of the special needs child without those assets being included in determining eligibility for public benefits. Generally speaking, monies in the trust can be used to pay for items that are not provided by the public benefit system. For example, money in the trust can buy a television, or pay for a companion, or pay for a vacation. An attorney who specializes in the area of special needs planning is necessary when preparing this type of trust. A good place to start looking for such an attorney is the Special Needs Alliance, [www.specialneedsalliance.org](http://www.specialneedsalliance.org). There are different types of Supplemental Needs Trusts to consider and review with your attorney.

## Advance Directives

Advance Directives allow a person to appoint someone to assist with financial and health care decisions if they are unable to themselves. The most common advance directives are Powers of



**Sheryl R. Frishman, Esq**

your child is taken care of properly. This is the case whether your child is "cured" or not. Here are five things you can do to give yourself greater peace of mind and to protect your family: Prepare a Letter of Intent; Execute a Will; Create a Supplemental Needs Trust; Sign Advance Directives; and Obtain Guardianship.

Attorney (financial decisions), Health Care Proxies, and Living Wills (medical decisions). Advance directives may also be an effective tool for the special needs child who does not meet the criteria for a guardianship (more fully discussed below).

## Guardianship

Parents of a special needs child, or any child for that matter, are considered the natural guardians until the child reaches the age of 18. After 18 the child is emancipated regardless of their functioning level. Obtaining guardianship enables parents and relatives to ensure that they or others that they designate may act as advocates with legal authority and maximize all necessary and available supports and resources for the special needs child who requires some level assistance in managing their personal and/or financial affairs. In order to obtain guardianship, a court proceeding needs to be commenced. There are different types of guardianships, for example a guardianship that is plenary (covers everything), or one that is specifically tailored for the specific needs of the child (i.e., the child can take care of themselves in certain ways but needs assistance with certain aspects of their life). The guardianship that is right for your child can be determined with your special needs planning attorney.

## Follow-Up

Once the above mentioned five tools are put into place, it is important to se-

## Letter of Intent

In order to get into the planning "mode" we ask parents to think for a moment what would happen if they were to die tomorrow? Who would be equipped to step into their shoes and take care of their special child? Who knows the child's likes and dislikes, their dreams and their fears? It is important for all parents of children with special needs, and even parents of typical children, to have a Letter of Intent which will help the people that will be caring for the child interpret your hopes and desires for that child. A Letter of Intent is not a document that is prepared by an attorney, nor is it a formal legal document. However, the people caring for your child will heavily rely on the letter for guidance after your demise. By compiling as much information about your child and his/her needs and your desires, you will be giving future care providers the knowledge and insight they will need to provide the best possible care for your child. Caretakers will not have to waste precious time learning how to manage and care for your child. This is not an easy letter to draft; it is very emotional and difficult. However, all parents must go through this very difficult step to ensure a well-planned future for their special

lect a combination of resources that will ensure adequate funds for your child's lifetime, such as insurance, savings, investments, family assistance, etc. Your special needs planning attorney can work with insurance and investment professionals to facilitate this. It will also be important to review the beneficiaries of all "non probate assets" i.e., employer sponsored retirement plans, IRAs, KEOGHs, life insurance policies, etc. Additionally, it is important to hold a meeting with all interested parties, i.e., the Guardian(s), all Trustees and Successor Trustees and all siblings; and any other interested relatives, to review the estate planning documents, and to discuss the plan. Finally, it is important to review all documents periodically, especially if the child's condition changes or the parents' economic situation changes.

There is nothing we hope for more than science to come up with a cure for Autism. Unfortunately, this has not happened to date. Thus, it is imperative that you plan for the worst, but continue to hope for the best. Not planning could be devastating to the child that you are trying so desperately to help. There are tools available to ensure that your child will be taken care of regardless of what science finds. It is strongly recommended that you take advantage of the opportunity to plan while you are still able to do so.

*Nothing in this article should be construed as legal advice. Please consult with an attorney regarding your own particular situation.*