

Winter August 2012

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### Repository Citation

Toske, Terry L. (2012) "Special Needs Estate Planning-A Family Perspective," *Marquette Elder's Advisor*. Vol. 2: Iss. 3, Article 5.

Available at: <https://scholarship.law.marquette.edu/elders/vol2/iss3/5>

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# Special Needs Estate Planning—A Family Perspective

*A good family plan to help a disabled member will contain a detailed allocation of responsibility for each family member, when everyone knows upfront who will be handling the money and who will be making the doctor appointments, all benefit from a job well done.*

**By Terry L. Toske**

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When I was asked to write an article for *Elder's Advisor* several months ago, my first thought was that I was truly honored and complimented that this group of attorneys would actually want information from me! After all, I am not an attorney, nor a paralegal, nor do I have a long list of initials after my name.

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*Terry L. Toske* is the former Executive Director of the ASSOCIATION for the RIGHTS of CITIZENS with handicaps, Inc. (ARCh) in Waukesha, Wisconsin. Ms. Toske has over twenty-eight years of experience working with individuals who have developmental disabilities and their families. She currently provides consulting services to ARCh and other organizations.

Then, the fear set in. What could I say to this esteemed group that would have impact and relevance? How would I say it? I took the time to read the last issue of *Elder's Advisor*, which served to reinforce my initial fears. I do not have legal cases to cite, nor will you find a "selected bibliography" at the end of this article. It took me some time (as I believe most good decisions and revelations do), but I came to grips with myself (and my self-esteem) and realized that I do have valuable and important things to say, and possibly some lessons to teach that are not taught in law school. They are lessons of the heart, lessons of the Human Service Delivery System and experiential lessons of families who have a loved one who has a disability. They are critical lessons to be learned by those of us who work with people, especially those of us who give guidance and advice. I hope that I can take some of the lessons that I have learned from the families I have worked with over the past twenty-eight years, and share those valuable lessons with those of you who are professionals in the legal arena, thus helping you better serve your clients.

This article will focus on the critical importance of specialized financial and estate planning for people who have a family member with a disability. My area of expertise is working with individuals who have developmental and/or physical disabilities, and that is the group that will be highlighted and referenced throughout this article.

## **Who Should Engage in Specialized Planning?**

Planning for the future is important for all of us. We plan for retirement, we plan for our children's on-going education and many of us even plan for our funerals. For families with someone who has a

disability, planning is even more important, but too often is delayed, poorly done or just ignored.

You will notice that I have referred to families, not just parents. This is with specific intent. The first step in effective planning is identifying those families who need to do specialized planning, and that group includes *all* family members, not just parents. It is critical that intake protocol for *all* engaging in financial and estate planning includes the specific questions:

1. Do any of your immediate or extended family members have a disability or currently or potentially qualify for government benefits?  
and, if yes,
2. Do you intend to include them in your estate plan?

Too often, these questions are not asked, under the assumption that people will volunteer this information. They don't! Most times, people do not volunteer the information because they don't realize it has any importance. They do not know the rules, regulations, laws and pitfalls. This is particularly true with extended family members—those loving aunts, uncles, grandmas and grandpas, who just want to do a good thing for their “little one” that has some special needs. Little do they know that their generous and loving bequest could disqualify a loved one from government benefits that are needed to survive. They just wanted to help, after all! It is up to the professional doing the intake interview to ask necessary questions upfront and point-blank.

### The Importance of Planning

Families need to be educated as to why planning is important. Some may need to be convinced of the importance of planning for the future. Each family member will have a different reason for needing to plan and will derive different benefits from proactively planning for the future.

### Benefits of Planning for Parents

Parents of children who have disabilities will find added security and peace of mind when they engage in good planning. They will feel a sense of relief in having a better idea of what their child's future will be after they are no longer there to ensure that future themselves. Many parents, as well as entire families, make assumptions about their child's future. More families than one would think have *never* really talked with one another

about what will happen to their child with a disability when the parents die. Many assume that “government” will just take over, and that their son or daughter will go to a group home. Some assume that the other adult children in the family will take care of their brother or sister. Often, family members have contradictory assumptions, but they are unaware of these differences until a crisis occurs (parents die or are placed in a nursing home).

Planning gives parents an opportunity to prepare, proactively, for their child's future. Many families do not realize the amount of work and time planning can take. There are extensive waiting lists for most services for adults with disabilities, particularly for residential support services, and thus, preplanning is critical! A good plan will work to include all of the people involved in the life of the person with a disability, and will build a support team around that person. Having an established “team” is most certainly a huge asset for the person with a disability, but it also provides the family with a real sense of security in knowing that there is a committed group of people in place to look after this family member when the parents are gone.

Planning allows parents to establish some preferences for their child's lifestyle when the child is no longer residing with the parents. Unfortunately, parents cannot “pick” the group home, service, or service providers for their child unless they are privately paying for all services. If the parents intend to utilize county monies and county-contracted services, they will typically have little, if any, choice of providers. Parents can, however, make known their preferences for lifestyle and quality of life issues for their child. Quite honestly, these issues, some of which are noted below, are usually the most important to families.

- Religious preferences: Does the disabled family member go to church each week, and what church?
- Favorites: Do they have any favorite items, foods, and activities?
- Travel: Is there a special family vacation spot?
- Traditions: Are there special family traditions that should be maintained?

Parents are rightfully concerned with these issues. Such choices will truly lend to maintaining the quality of life for their children with disabilities after the parents' deaths.

Completing a thorough estate plan also allows parents to share the plan with extended family. For most of us, raising the subject of our estate plans (basically our ultimate demise) is a terribly uncomfortable thing to do. Nobody likes to talk about “when I die,” or “when you die.” However, that discussion is a critical one for these families. Further, extended family need to know about the issues of maintaining qualifications for entitlements so that they do not unknowingly disqualify a favorite grandchild, niece or nephew in their estate plan under the guise of trying to do a good thing.

### **Benefits of Planning for Other Family Members**

Planning eliminates much of the second-guessing and assumptions about the future by family members, particularly for the siblings of the child with a disability. Siblings, certainly as early as their teenage years and many times earlier, begin to wonder (and make assumptions) about who will take care of their brother or sister should anything happen to mom and dad. Although they wonder about it, they rarely, if ever, ask anyone about it or talk about it, even amongst themselves. This uncertainty can lead to disastrous results as the parents age if no planning takes place. Interestingly enough, when I have dealt with families, it is rare that the children's ideas and assumptions about “who will do what” match the thoughts and wishes of the parents! A good plan will contain a detailed allocation of responsibility for family members. Everyone knows up front who will be handling the money, who will be serving as guardian (if needed) and who will be making doctors appointments.

Planning allows family members to allocate responsibilities based on individual skills and circumstance of each family member. Think about your own family for a moment. Is there one family member who you would NOT want to handle YOUR money? Is there another who might be really good at dealing with your finances, but who you would not want making decisions about your medical care? That is certainly the case in most of our families. Planning should help families look at all these factors in allocating future responsibilities. How many families do you know who name the eldest son as the executor of the will just because he is the eldest son? It also makes absolutely no sense

to have the sister who lives 400 miles away serve as the guardian. It is virtually impossible to be a good guardian from that distance. When allocating these responsibilities, remember that a family can do one thing that no professional can do—be loving family members. Families need to plan on allocating time to just being family—no one else can do that job! Many other responsibilities may be better allocated to paid professionals (e.g., corporate trustees, attorneys, human service system providers, accountants) to ensure “time best spent and skills best used” by family members. Planning ideally done together as a family also may eliminate disagreements between family members before they have a chance to occur and while the parents are still alive to “set the record straight.”

There is a tremendous relief of burden for all family members when planning is done. Even if the plan itself is not perfect, the family members know what the plan is, have discussed it ahead of time and usually agree with it. The biggest fear is often the unknown, and families can help eliminate the unknown with a good solid plan.

### **Benefits for the Child With a Disability**

There is no doubt that the person who will benefit the most from planning is the individual who has a disability. This person also has the most to lose if planning is not done, or is not done well.

The family member with a disability needs to know there is a plan, and he or she needs to be a part of the development of that plan as much as possible. Even individuals who have significant disabilities know when there is turmoil and are affected by it. Often an individual who may not be able to communicate verbally will have significant behavioral issues due to the stress of family crisis and disharmony. The individual needs to have the plan explained to them to whatever extent of understanding is possible. Knowing what will happen gives that person some security and allows for a transitional period to occur.

Planning provides the opportunity to minimize the trauma of change for a family member with a disability. Change is difficult for all of us. For people who have disabilities, particularly for those who have mental retardation, change is even harder and more traumatic. Too often when a parent dies, the adult child with a disability has literally everything in their life changed in one instant—the

place they live, who they live with, the bed they sleep in, their schedule, the food they eat, the TV shows they watch—literally *everything in their life!* Such change would be difficult for any of us. For someone with limited capacity, change is beyond comprehension, devastating and harmful. When a plan is in place, transitional changes can occur over time in preparation for the future.

Most importantly, a good plan can ensure that the person has more than just the bare essentials of a poverty-level existence (which is what government benefits will provide). A plan allows a child with a disability to maintain the quality of life that their parents want.

### Entitlement Protection

As you are aware, the primary reason to have a specialized estate plan when a family member has a disability is to protect his or her government entitlements. But why?

Most adults who have disabilities (developmental or physical) will rely on SSI (Supplemental Security Income) and Title XIX as the primary means of support and as the primary payers of support services. Most families are aware of this, but rarely know the asset criteria for maintaining benefits. They rely on the expertise of the attorneys and human service professionals they are involved with for this information.

Most adults with disabilities will eventually have their SSI payment converted to Social Security Disabled Children's benefits upon their parent's retirement or death because the cash payment is usually higher. It is critical, however, that they maintain their eligibility for Title XIX. SSI or Social Security cash payments will typically cover the costs of food, clothing and shelter (meager as it may be). It is Title XIX, however, that is quickly becoming the primary funder of the support services due to the waiver systems. Title XIX is most often the funding source that pays for the staff time for in-home care and for his or her work-related services, transportation and medical care. These services are the biggest costs in providing continuing care for individuals who have disabilities throughout their lifetime. Maintaining qualification for Title XIX is CRUCIAL, and parents must be told this.

Government benefits will only provide for a poverty level (or below) existence. This fact is often shock for families. They have no idea!

Professionals need to assist families to move toward public/private partnerships to meet needs of the individual with a disability. Government may provide food, clothing, shelter and basic support services, but families and parents will need to provide (financially) for quality of life.

### Case Study 1: Mike and His Sons

*I received a call from the local hospital social worker regarding a patient in his seventies with terminal cancer who had been admitted through the emergency room. This gentleman, "Mike," had a 45-year-old son with mental retardation. For the past four days of Mike's hospital stay, the son had been sleeping in the chair in the hospital room because he had no place to go and no one to look after him. The hospital staff was very concerned because Mike's cancer was progressing, and his prognosis was poor. Mike would have six months to live at best (one doctor thought it would be closer to eight weeks). No one on staff knew what to do. But, they did know that the next hospital stay for Mike would be an unpleasant one and that his son would not be able to sleep in his room.*

*When I met with Mike and his son James, I learned that James had been virtually raised at state institutions as a child, and then returned home twenty years ago. The family had received no services from anyone during that entire time and were unaware of available services, or how to access them. The institution had "closed the case," and thus destroyed all of James' records. I was able to link Mike with a qualified attorney to get his estate plan in order since his will was quite out of date. Furthermore, his wife had Alzheimer's disease and had been living in a nursing home for a number of years already.*

*As part of Mike's planning, we helped him develop a standby emergency plan for his next hospitalization, submitted applications for SSI and Title XIX benefits for James, and began the evaluation process with the county human services department. (This department initially told Mike that there would be a ten year wait for placement and, even with intervention, took over two months to process an "emergency application for evaluation.") Mike's attorney was able to help him establish a special needs trust for James as well as make provisions for his wife in the nursing home.*

*Mike passed away this past fall. James has been reunited with his brother. (Because of a fam-*

ily rift, the brother had not had contact with Mike, Mom or James for over twenty years until the planning process started.) A plan is now in place to help James understand what is going on (past, present and future). (Even though he had been in the hospital room and lawyer's office during all of these discussions, no one had explained anything to him!) We are developing another plan as a continuing effort to link James with additional services. For the time being, he goes to work with his brother every day and "hangs out." He has been sleeping on his brother's couch in the living room for over seven months now, and remains on waiting lists.

Mike's case is one of too little, too late. At least we were able to take care of most of the financial and estate pieces. The human service delivery systems' wheels turn slowly. With a good plan in place well ahead of time, this bad situation could have been avoided. The past seven months have been very traumatic for James, his brother, and his brother's wife and children, all of whom have had major life style changes as a result of Mike's death. The saddest part is that most of this trauma and hardship could have been avoided.

### Case Study 2: The Major Family

*The Major Family consists of seven brothers and sisters. Five of them are married (so add five in-laws to the mix), and one (Susan) has mental retardation. Mom and Dad are both deceased, with Mom having just passed away last summer. Mom had a will, and she and her attorney knew that for Susan to maintain her benefits, she could not have any assets. Consequently, they disinherited her in the will, leaving equal shares of the estate to the remaining six siblings. Mom's assumption was that the brothers and sisters would take care of Susan. The estate has not yet been settled or divided.*

*All of the siblings agree that they will help care for and provide for Susan, but none of them agree on who, how, where, why or how much! One wants everyone to give everything to Susan, and refuses to sign off until that happens. Another wants to pay the brother whom Susan is living with to care for her. Another thinks the other is doing wrong . . . the list goes on and on. Meanwhile, Susan continues to eat and gain weight, to the point that she is having problems with her feet and ankles, resulting in problems at work with her sta-*

*mina. Half the siblings will not talk to the other half, and Susan is in the middle, feeling everything is her fault (which is most likely why she is eating so much). Everyone is miserable. This was certainly not Mom's intent.*

The lack of a plan, even in a close and loving family, can wreak havoc. Amazingly (at least it was amazing to me) the entire estate in question, including the house, all of the contents of the house and the car is under \$200,000. Had there been a special needs trust, and a clear plan of action, with all of the family members involved in the planning process, many problems would have been avoided. Susan would now be enjoying the loving support of all of her brothers and sisters.

### Summary, or "So What Should I Do Now?"

When performing estate and financial planning, this checklist is a good starting point:

1. ALWAYS ask if there is a family member that has a disability. If there is, help the family begin the planning process with these steps:
2. Establish a team approach to planning. The team should include the following members:
  - a. Attorney
  - b. Financial planning professional
  - c. Social service agency representative
  - d. Family members
  - e. The person with a disability (in whatever capacity is possible for them)
  - f. Others as identified by the team

Each person on the team has his or her own distinct area of expertise that is needed in working to develop of good and complete plan for an individual who has a disability.
3. Empower the parents and other family members with information. Do not assume they know SSI rules or the human service delivery system. They probably don't.
4. Don't encourage parents to jump into guardianship. It should be a last resort, not a first alternative.
5. Encourage parents to talk openly about the need for estate and financial planning and their special planning needs with their extended families. The parent must be strongly encouraged to tell their parents, aunts, uncles and siblings not to leave monies directly to the child with a disability.

The systems that we work in as professionals are complex. I could (and have) confused many attorneys and financial planners with a unique recipe of acronyms and language particular to my field of expertise. You legal and financial professionals have done the same to me! The terminology, acronyms and information that are truly basic

to each of us as professionals in our own arenas are as foreign as foreign can be to most of the families we deal with. We must look at the world from their perspective, using a common language, to help them achieve and understand the information that is critical to their futures.