

# Estate Planning Getting Started

by Frank L. Brunetti

Estate planning always involves difficult decisions. The process is even more complicated for those families who must be concerned with the care, comfort and well-being of a child with disabilities, especially if it is clear that the child is unlikely to be able to provide for his or her own support or make mature day-to-day decisions. Such parents often worry about who will care for a son or daughter after their deaths; they also worry about ensuring that the child's needs will be provided for financially.

To begin the estate planning process, parents must focus on two tasks. The first is to perform an "inventory." The second is to retain an attorney with expertise in estate planning for children with disabilities.

## The inventory

An "inventory" involves gathering and putting into order the most important documents that your fiduciary will need for the care of your child. (A "fiduciary" is the person you have selected as the personal representative of your estate, such as an executor, a trustee or both.) This inventory, which, for ease of reference can be kept in a three-ring binder, will include the following sections:

- **Part I: The Profile**—The profile should cover important information about the child's educational, therapeutic and medical history. It should include names, addresses and phone numbers for all the child's doctors, therapists and other service providers. It should also include key medical records, along with the names and dosages of all current medications. Finally, the profile should offer a complete description of the child's disability, and its likely effects on the child's life, both now and in the future.
- **Part II: Documents**—This section of the inventory should include the following: the child's birth certificate (original or duplicate copy), the child's social security number, parents' social security numbers, name and address of the parents' estate planning attorney, name and address of the child's school or day care provider and a guardianship order and/or any other legal documents regarding the legal status of the child in the case that parents become unable to maintain responsibility for his or her care.
- **Part III: Living Plan**—A plan, written by the parents, describing how they expect the child to live out his or her life. The life plan should cover everything from the child's favorite activities and foods, to a list of friends and relatives—those with whom the child may live, others with whom the child should maintain contact. The plan should also include burial instructions for the child.

The preparation of the "living plan" need not be a "parent-only" task. In many cases, the child and other family members can participate in the process and may contribute useful information and ideas.

## Finding an attorney

While parents are completing the inventory, they can take steps to find an attorney who has experience in estate planning for children with disabilities. Parent organizations or Parent Training and Information centers may be able to refer parents to a local attorney with expertise in this area. County bar associations may be another referral source.

It is important to retain an attorney with specialized knowledge because estate planning for a child with disabilities requires knowledge of federal tax law; regulations governing SSI, or

"Supplemental Security Income," the federal program that pays a monthly stipend to people with disabilities, dependent on income but regardless of age; state guardianship law and state Medicaid regulations. In addition, some states have enacted special legislation related to estate planning for children with disabilities. For example, certain states allow the establishment of "community trusts," nonprofit organizations that pool resources for the benefit of people with severe disabilities. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as administration of trust funds, advocacy (for example, participation by community trust representatives in the development of individualized plans developed by service providers) and/or guardianship.

Typically, most attorneys will give a free or reduced-rate initial interview. Parents should go to the initial interview with a specific goal—to determine whether this attorney can properly serve their needs, and for a reasonable fee. To be capable of making this determination, parents need to know something about relevant legal issues before going to the interview. These issues might include the Medicaid "resource" rule (the way their home state considers assets when determining eligibility for Medicaid coverage) and regulations for establishing legal guardianships in that particular state. This type of information is available through various publications and national organizations.

### **Financial needs and liquidity**

Before the estate planning process can begin in earnest, parents must determine the financial condition of their estate and decide if and to what extent their estate will provide for beneficiaries other than the child with a disability (for example, siblings). They will need to prepare an updated financial statement, as well as a family profile that outlines their particular estate planning needs. For example, if parents' assets include a family-owned business, they need to consider whether the business will be passed on to heirs or be sold. If the business is to be inherited by children in the family, the estate planner must find a way to pass the business on to the designated heirs without its assets being depleted by estate or inheritance taxes. If it is to be sold, sales arrangements should be made as part of the estate planning process.

Many families face the common estate planning problem of liquidity. "Liquidity" refers to cash or the ease with which other assets can be converted into cash. Because treasury bonds can be easily converted into cash, they would be considered "liquid assets." Real estate, on the other hand, would be considered "illiquid."

Liquidity is an important estate planning issue because parents need to determine whether their estate will have enough cash to pay for liabilities such as federal and local estate/inheritance taxes. In addition, if parents hope to set aside funds for the care of a child with disabilities, they need to think about where these funds will come from. Do they need to purchase life insurance, or should they transfer new or existing insurance coverage to an irrevocable inter vivos trust (a trust established during the lifetime of its creator, which cannot be revoked)?

### **Writing a will**

Once these preliminary steps have been completed, parents can begin drawing up a will. Because many forms of government assistance are denied to individuals with substantial assets, the will must exclude the child with a disability from inheriting or find an alternative way—such as a "special needs trust"—to maintain the child's eligibility for benefits and insulate the inheritance from government claims seeking reimbursement of previously paid benefits.

Another important feature of the will is the appointment of the executor (or executrix). The executor is the person charged with making sure the will's provisions are carried out. The executor must gather the assets, pay the liabilities, file tax returns and fund any trusts. Typically,

the executor will be a family member or close friend. In some cases, particularly with complex estates, the executor may be a bank or trust company. An attorney or accountant usually assists the executor in handling the estate.

If the will provides for a trust, a trustee must be appointed to manage the trust until its termination. While the executor's term will be short-lived, the trustee may serve for years, even decades. Next to selecting a guardian, the choice of a trustee is the most difficult decision. The trustee must have several qualities: trustworthiness, sensitivity to the physical and emotional needs of the child with disabilities and ability to handle the financial affairs of the trust. A trustee must act almost as a surrogate for the parent. In some cases, two trustees may be needed—one to administer the financial aspects of the trust and another to carry out the more personal duties of the trustee such as personal visits with the child and advocacy on his or her behalf.

In addition, the parents must have properly drafted "powers of attorney," which grant another person the legal authority to carry out their affairs if they become unable to do so. In this event, it will be important that another individual is ready and willing to take on the role of "successor legal guardian," a role that gives this person legal responsibility to care for and act on behalf of the child with disabilities.

It's only human to put off making difficult decisions, but in most cases, parents of children with disabilities will have started the estate planning process without necessarily labeling it as such. Most parents will have information needed for an "inventory" readily available—though perhaps not yet organized in a three-ring binder. Many parents have already drafted a "living plan"—in their minds if not in writing. Some parents may have already discussed the issue with an attorney. All that remains is some basic organization and a decision to complete the estate plan within a specific time frame.

Frank L. Brunetti is an attorney and Professor of Law and Taxation at Fairleigh Dickinson University in Teaneck, New Jersey, and maintains a tax practice in Hackensack, New Jersey. Mr. Brunetti has written for the Estate Planning Journal on the topic of estate planning for families who have children with disabilities. He also is an author and lecturer for specialized tax courses sponsored by the American Institute of Certified Public Accountants.

## Choosing the Ideal Trustee of Your Child's Special Needs Trust

By Stephen W. Dale

I am a former psychiatric nurse of seventeen years who later became an attorney with the objective of fighting against abuse and neglect in large institutions. As my practice developed, my primary focus has been drafting and advising on Special Needs Trusts. This is a rapidly developing area of the law, and after watching hundreds of Special Needs Trusts under administration, I have come to the conclusion that the selection of a trustee is the greatest factor in whether a Special Needs Trust succeeds or fails.

To begin, let's review the mechanics of trusts in general and then focus on Special Needs Trusts specifically. The best way to understand how trusts work is to think of a trust as a contract. The most common type of trust today is the Living Trust, which is used to avoid probate. A Living Trust can avoid probate because the settlor (creator) of the trust designates where the trust's assets will pass to specific beneficiaries at a given time. This usually occurs when the settlor dies. If you place your home in the trust or contract, the home passes to your heirs in accordance with your contract, not by state probate law, which allows families to avoid the costs and delays of probate.

The central purpose of a Special Needs Trust is to set aside assets for a disabled beneficiary without elimination of the beneficiary's eligibility for "needs based" public benefits such as SSI or Medicaid. A Special Needs Trust can accomplish this because the Social Security Administration does not count Special Needs Trusts as assets of a SSI or Medicaid recipient. This is only the case if the trustee has full discretion of time, purpose and amount of distributions. A Special Needs Trust works because the trustee has the ability to deny any request even if the beneficiary's request is entirely reasonable. When parents create a Special Needs Trust for their son or daughter, they are creating a contract that is empowering the trustee with the ability to never make a single distribution if the trustee so desires.

As a Special Needs Trust attorney, my job is to create trusts that take the control of assets away from a disabled beneficiary, even if the beneficiary is capable of managing those assets. In many ways this is an insane thing to do—to create a contract that tells a trustee that they can take care of your child, or not take care of your child, at the trustee's absolute discretion. When setting up a Special Needs Trust, parents should not take lightly the potential problem this creates.

### Choosing a Trustee of a Special Needs Trust

Finding the "ideal trustee" is a near impossible task. This individual or entity would need to possess numerous skills on top of dedicating themselves entirely to the needs and advocacy of another for potentially the remainder of their own existence, and beyond. However, you can achieve success if you take all of the attributes of the ideal trustee and divide them into three categories. A system of checks and balances creates a stable trust administration formula and can do much more than protect public benefits.

#### Category One—Financial Duties

All trusts have certain duties concerning handling investments, tax planning and maintaining books. The discretionary nature of a Special Needs Trust intensifies those needs, especially when the beneficiary needs assistance advocating for their needs. Oddly enough, the trustee may have no legal obligation to make a single distribution from the trust, but does have the duty to make "prudent investments." The trustee has a duty to oversee the investments in the trust and diversify them so that they are neither too conservative nor too aggressive. For example, if the trustee of a \$500,000 Special Needs Trust invested all of the funds in a Certificate of Deposit, receiving a one percent return, while a properly balanced portfolio would make a seven percent return, the trustee could be liable to the trust for the difference. Contrarily, if the trustee invested in risky growth funds and lost value in the trust, the trustee would be responsible for the

difference between the loss and expected rate of return, had the funds been properly invested. This duty is governed by individual state laws, but the principal is pretty much universal.

### **Category Two—Personal Needs and Advocacy**

The second category is providing for the disabled beneficiary's personal needs. These needs include factoring how distributions will affect eligibility for public benefits, adhering to the ultimate intent of the trust document and, in many cases, advocating for the care and safety of the beneficiary. It is imperative that parents think beyond maintaining their child's eligibility for government benefits and think more broadly when creating an estate plan to provide for their child. Especially when the beneficiary may need assistance in advocating for their own needs.

I believe the advocacy duties are the most important task of the trustee. Whenever I think about this need, I remember a woman named Mrs. Miller who represents many mothers of children with disabilities. Mrs. Miller was an uncompromising advocate for her son David. David had hydrocephalus, a condition where he could only be out of bed a couple of hours a day and he needed regular range of motion exercises to prevent contractures. It was extremely important that his beddings be dry at all times because his skin could deteriorate in a relatively short timeframe. Mrs. Miller had a habit of showing up at the unit any time of the day or night without notice. When she would enter the unit she would race to her son's room and place her hand on her son's bed to see if it was dry. On the rare occasion when the bed was not dry, Mrs. Miller would make a beeline for the nursing supervisors' office and the nurse responsible for David that day would get severely reprimanded. Mrs. Miller passed away during my time in that unit and I remember the staff discussing their relief that she never put her hand on her son's bed again. Now, this was a very fine unit and he continued to receive top care, but in a lesser unit, without his mother's advocacy, this would be the beginning of declining care for David.

The ideal trustee must continue advocacy upon the parents' incapacity or death. In other words, the ideal trustee makes sure the bed is dry for the remainder of the lifetime of the Special Needs Trust beneficiary. It may be very desirable to put a provision in the Special Needs Trust that when family or friends are unable or unwilling to visit the beneficiary, the trustee should employ a private care manager to visit the beneficiary unannounced for the remainder of the beneficiary's life.

### **Category Three—Accountability and Keeping the Special Needs Trust on Track**

Accountability involves reviewing the activities of the trustee and other advisors. If, for instance, the beneficiary of the Special Needs Trust is a 12-year-old boy with autism, it is very possible that he could live for another 75 years or longer. How likely is it that you can select a person or entity that can guarantee to meet his needs for the next 75 years? In fact, what is the likelihood that the public benefits system and government programs that provide for his needs today will resemble the system 30 years from now?

If we establish a checks and balance system, then someone should independently review the performance of the trust and have the power to replace any party that is not able or willing to meet the trust objectives. This person or entity can also amend the trust to conform to changes in the system and the law as time goes on. In some cases the person or entity might be an advisory committee of family, friends and professional care managers. This could also be what is called a Trust Protector—a person or entity that has specific powers to amend or revise the trust as well as replace trustees.

### **Family and Friends as Trustee**

There is always an inclination to appoint family members as successor-trustees of Special Needs Trusts. Many trusts fail because of ill equipped trustees, no matter how well intentioned. While appointing a family member may be convenient and seem like the best thing to do, private professional trustees and even banks who serve as trustees often outperform family members in

the same role. In addition, the need for attorney advisement and the risk of a benefits battle is greatly reduced when a trust is directed by an experienced professional trustee.

With the exception of smaller trusts, professionals are better equipped to handle the job. Generally speaking, most corporate trustees or banks require a minimum of \$200,000 in a trust to be cost effective. California and other states have a developing profession of private professional fiduciaries, many who are experienced in the management of Special Needs Trusts and work on an hourly basis.

This does not mean that family should not be included. This means only that they play more of a supervisory role.

Let us look at three models that have proven effective. Keep in mind that the right model depends on your child's needs and resources in your community.

### **MODEL 1—The Trustee is Directed By A Trust Advisory Committee**

One very popular model is to have a corporate fiduciary, bank or private professional fiduciary, serve as trustee, under the direction of an advisory committee. The committee would be comprised of one or two family members or friends and a trust adviser who can direct distributions by maximizing utilization of public benefits to meet the trusts' overall objectives.

There are a growing number of corporate trustees or banks that are doing a good job in administration of Special Needs Trusts. This is counterintuitive for many families and the image in their minds is an impersonal bank employee who doesn't know or care about their son or daughter. This has become big business for corporate trustees and they are becoming more competitive and responsive to meet this need. Despite this development, there are certain things that corporate trustees are well equipped to do and other things they are not equipped to do. Corporate trustees are proficient at managing funds with a focus on the specific needs of the beneficiary. However, They are not a social service organization. They will usually need assistance with how the distribution will affect public benefits, and normally do not provide direct advocacy for the disabled beneficiary. A growing trend is for corporate trustees to contract with advisory groups that provide the social service needs of their beneficiaries. The advisory committee would have the duty to direct how distributions are made, review the performance of the professional trustee and replace that trustee with someone else if the need arises.

### **MODEL 2—The Trustee is Directed By A Care Manager**

This option is ideal for beneficiaries with severe health care needs or for many persons diagnosed with a mental illnesses. In this case, the professional trustee is directed by a care manager who interacts directly with the beneficiary while the trustee heads-up the funds. A third party, the trust protector, oversees the trustee and the care manager from a distance and can replace either at will.

For example, John is a young man in his late 30's with bipolar disease. His parents want to set up a trust, but are concerned that naming their other children will pose as a terrible burden, and yet they have no one else to turn to. As is very common in these cases, John's condition has severe highs and lows, and the greatest factor in his stability was taking his medication regularly and complying with prescribed treatment. John has a long history of resistance to treatment especially when family was concerned. The answer in that case was to name a local bank as the trustee with a local psychiatric social worker as the private case manager. The case manager visited with John periodically, checked with him as far as compliance with his treatment, and distributions by the bank were based on the care managers' recommendation.

The siblings were listed only as Trust Protectors with their sole duty to review the performance of the trustee and care manager with the power to replace those entities if they did not perform their duties in the best interest of their brother. In addition, they could amend the trust to comply with changes in the law.

### **MODEL 3—Co-Trustees**

This option is for smaller trusts or when a trustee can advocate for themselves. For instance, it is very common to leave a competent disabled beneficiary a home which is excluded for purposes of eligibility from virtually all government benefit programs. If the family also leaves \$50,000 in a Special Needs Trust for upkeep of the home, a professional trustee may not be cost effective. The answer may be to have several persons as co-trustees who make distributions under the direction of an experienced advisor or attorney that specializes in Special Needs Trusts. In many cases, the family CPA may also make a good co-trustee or advisor. When multiple people are involved with the management of a trust, it is less likely that the trust will fail to make a distribution that is in the beneficiary's best interest.

#### **Which is the Right Model?**

These are not the only options in choosing a management team and the best advice is to compile a management team that best suits a beneficiary and trustee's needs. Your attorney should be your guide in this matter. Keep in mind when you are setting up a Special Needs Trust that you are buying the law office's experience and not merely purchasing a document. When interviewing a law office, focus on their experience with Special Needs Trusts and ask them to guide you to the right resources in your community to seek the ideal trustee. The offices with the most experience usually assist in structuring personal injury settlement into Special Needs Trusts because in those cases administration begins immediately.

Make sure that your document sets up a system of checks and balances. It should include provisions that modify the trust as laws or circumstances change. The document should also provide the ability for an advisory committee or trust protector to replace the trustee if they do not fulfill their duties or a better option becomes available. Many nonprofit organizations are setting up programs that may be very desirable, but make sure the program has a positive track record.

Deciding which model to use will depend on the unique needs of the beneficiary, the amount of money invested in the trust, the need for advocacy and care managers and the proximity of the trustee or advisory committee members.

*For more information on The Special Needs Alliance visit [www.specialneedsalliance.com](http://www.specialneedsalliance.com) or call 1-877-572-8472.*

## **The Letter of Intent**

(originally published in the News Digest)

by Richard W. Fee

What is the Letter of Intent? Simply put, the Letter of Intent is a document written by you (the parents or guardians) or other family members that describes your son or daughter's history, his or her current status, and what you hope for him or her in the future. You would be wise to write this letter today and add to it as the years go by, updating it when information about your son or daughter changes. To the maximum extent possible, it is also a good idea to involve your child in the writing of this Letter, so that the Letter truly "presents" and represents your child. The Letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

Even though the Letter of Intent is not a legal document, the courts and others can rely upon the Letter for guidance in understanding your son or daughter and the wishes of you, the parents. In this way, you can continue to "speak out" on behalf of your son or daughter, providing insight and knowledge about his or her own best possible care.

### **Why is it Important to Write a Letter of Intent?**

A Letter of Intent serves many purposes. First, it spells out in black and white your son or daughter's background and history and his or her present situation. It also describes your wishes, hopes, and desires for his or her future care and, where possible, describes your child's feelings about the present and desires for the future. While you are still living, the Letter can be used by your lawyers and financial planners to draft the proper legal documents (wills and/or trusts) to ensure your wishes are carried out. Once you are no longer able to take care of your son or daughter, due to death or illness — and this is the most important reason to write a Letter of Intent — the Letter gives your son or daughter's future caregivers some insight into how to care for him or her. It provides advice on possible alternatives for his or her care. If your child has a severe disability, caregivers will not have to waste precious time learning the most appropriate behavior or medical management techniques to use. If your child is used to doing things independently and only requires occasional assistance, the Letter can spell out exactly what is needed.

The Letter of Intent can describe this very concrete information and much, much more, including valuable information about the personality of your son or daughter — his or her likes, dislikes, talents, special problems, and strengths. Thus, the Letter is a crucial part of any life or estate plan, because it speaks both for and about the person with a disability and his or her family.

### **When Should Parents Write the Letter of Intent?**

The answer is a simple one. Start now. Start today. Procrastination is easy, when your health is good, the future looks bright, and there are a hundred other pressing tasks to be done. But none of us can predict the future. What will happen to your son or daughter, if something happens to you? Will your relatives, friends, lawyer, or the police know where to contact your son or daughter - and will that person know enough about your loved one to know what kind of care is needed and how best to provide it?

Writing the Letter of Intent now is a way to protect your son or daughter from unnecessary chaos and turmoil when he or she must depend upon someone other than you for the care and support that is necessary. The Letter of Intent helps pave your son or daughter's transition by giving future caregivers the information about him or her that they so vitally need.

Preparing the Letter is often an emotional experience for parents and their children. You will need self-discipline and motivation to work past the many painful questions and issues that must be addressed when considering your son or daughter's future.



### **What Information Goes Into the Letter of Intent?**

How can you summarize the life of a person you have watched grow and develop over many years? What can you say that will give insight into and perhaps touch the heart of a care provider who must suddenly assume some measure of responsibility for your son or daughter?

Basically, the procedures for developing a Letter of Intent are fairly simple. You can write the Letter out longhand, or you can use a computer or typewriter. Don't worry about perfect spelling or grammar; your major concern is that anyone who reads the Letter in the future can understand exactly what you meant and what you would like to see happen in your son or daughter's life. Begin by addressing the Letter to "To Whom It May Concern." In the first paragraph list the current names, addresses, and telephone numbers of the people who should be contacted if anything should happen to you (i.e., other children, case manager, your son or daughter's school principal or employer, lawyer, financial planner, priest, etc.). You might then briefly state the family history; include names, birthdates, and addresses of family members.

The Letter will then need to focus in upon seven potentially major areas of your son or daughter's past, present, and future life. Depending upon your child's needs, these areas may be: housing/residential care, education, employment, medical history and care, behavior management, social environment, and religious environment. You might begin by summarizing your son or daughter's background and present status in each of these areas. Then summarize your wishes, hopes, and desires for his or her "best" future, listing three or four options in each of these areas. Be sure to discuss your ideas with your son or daughter and to take into consideration his or her feelings on the future (more is said about this below). The worksheet shown at the end of this article is useful for this "future planning" step, which may require much thought and planning before you actually begin to write information into the Letter of Intent.

Take a brief look at the example below (marked "An Example for Writing a Letter of Intent"). This example focuses on only one of the major life areas— Housing/Residential Care — and illustrates how a person named Mrs. Sanders went about writing this section of her Letter of Intent for her son named Chris, a 35 year old man with developmental disabilities.

### **How Do I Involve My Son or Daughter in Writing the Letter?**

How much you involve your son or daughter in writing the Letter of Intent will depend in large part upon his or her age and the nature and severity of the disability. It is only fitting that young adults and adult children be involved in planning their own lives to the maximum extent possible. Many individuals have disabilities that do not prevent their full or partial participation in the Letter-writing process. Before involving your child, however, you, as parents, might want to talk first among yourselves about the content of the Letter and your ideas regarding your child's future. When you've agreed upon the basic information you feel should go in the Letter, discuss each area with your son or daughter. Ask for your child's input about his or her favorite things to do, what type of education has been enjoyable and what might be pursued in the future, what type of employment he or she enjoys or envisions. Equally crucial to discuss are your child's future living arrangements: How does your child feel about the options you are considering listing in the Letter of Intent?

It's important that your child realize that the Letter is not a binding, legal document; it is written to give guidance, not edicts, to all those involved in caregiving in the future. If you fear that your child will be upset by talking about a future that does not involve you as parents, then you may wish to make the discussion simply about the future — what will happen when your child leaves high school or a postsecondary training program, what your child wants to be or do in the next ten years, where he or she wants to live. You may be surprised to find that discussing the future actually relieves your child. He or she may very well be worrying about what will happen when you are no longer there to provide whatever assistance is needed.

Involving your child in discussing and making decisions about the future may be more difficult if the individual has a disability that severely limits his or her ability to communicate or to judge between a variety of options. You, as parents, are probably the best judges of how much — and how — you can involve a son or daughter with a severe cognitive disability. For these children, the Letter is especially critical; it will serve to communicate the vital information about themselves that they cannot.

## What Happens Once the Letter of Intent Is Written?

Once you've written the Letter of Intent about your son or daughter, the first, most important thing to do is to let people know that there is a Letter of Intent available to be consulted. This might mean telling your other children (or relatives, neighbors, friends, workshop director, pastor, or case manager) why you have written the Letter, what type of information it contains, and where the Letter can be found. Put the Letter in an easily accessible place, and make it clearly identifiable. Many parents also make copies of the Letter and give it to their other children (or persons such as a neighbor).

Secondly, you should update the Letter on a regular basis. Select one day out of each year (such as the last day of school or perhaps your son or daughter's birthday) where you will review what you have written and add any new information of importance. Talk with your child each time and incorporate his or her ideas. After each addition, sign and date the Letter. Should something change in your son or daughter's life, such as his or her caseworker or the medication he or she is taking, update the Letter immediately.

### **In Conclusion...**

Will your Letter of Intent overcome all of the obstacles to your son or daughter's transition into someone else's care? No, of course not. However, the Letter is of immediate usefulness in coping with your son or daughter's changed situation and, in the long term, will certainly help care providers understand and care for your loved one.

### **An Example For Writing a Letter of Intent**

Titling a section of her Letter "Housing/Residential Care," Mrs. Sanders writes that Chris has always lived at home and had a room to himself. She briefly describes the family home and the articles in the home that give Chris special pleasure, such as his portable radio.

She then describes his daily and weekly routine, including the fact that Chris finds great joy in going to dances each week at the local Arc. She briefly lists his favorite clothing, food, games, and so on. She also mentions that each year Chris visits his sister for a week in the summer.

Mrs. Sanders then considers what future living arrangements might be suitable for Chris, and she uses the worksheet at the end of this article ("Letter of Intent Worksheet") to jot down three options. Before she transfers these options from the worksheet to her Letter of Intent, she discusses each one with Chris. She does so because he needs to be a key member of the team planning his future life.

Following her talk with Chris, Mrs. Sanders lists the agreed upon information in her Letter of Intent. The first option she lists is the possibility that Chris might live with his sister. As a second possibility, he might live with an old family friend. The third option is residence in a group home. Because this last option may indeed be the one that is finally selected for Chris, Mrs. Sanders takes care to describe the type of group home she thinks he would enjoy. As a mother and lifelong friend to Chris, she sees past his limitations to his strengths, and she notes these down in some detail. Lastly, she expresses her desire that the group home will give him room to grow and build upon those strengths.

"Residential Care" is just one important area for Mrs. Sanders to cover in her Letter of Intent. It takes her a week to complete the other sections. She finds that describing the past is not nearly as difficult as considering the future, but she methodically and systematically works her way through each area, using the worksheet when planning is necessary. The end result is a Letter of Intent that is twelve pages long, handwritten. She feels comfortable that anyone picking up this Letter of Intent will have a head start in getting to know and care for Chris.

## LETTER OF INTENT WORKSHEET: CONSIDERING YOUR SON OR DAUGHTER'S FUTURE

For each applicable area below, consider your son or daughter's future. List 3-4 options to guide future caregivers in decision making and interaction with your child. Draw upon what you know about your son or daughter, through observation and through discussion with your child, and share what you've learned!

### **Residence:**

If something should happen to you tomorrow, where will your son or daughter live?

- 1.
- 2.
- 3.
- 4.

### **Education:**

You have a lifelong perspective of your son or daughter's capabilities. Share it!

- 1.
- 2.
- 3.
- 4.

### **Employment:**

What has your son or daughter enjoyed? Consider his or her goals, aspirations, limitations, etc.

- 1.
- 2.
- 3.
- 4.

### **Medical Care:**

What has and has not worked with your son or daughter? What should future caregivers know?

- 1.
- 2.
- 3.
- 4.

### **Behavior Management:**

What consistent approach has worked best in your absence during difficult transition periods in your son or daughter's life?

- 1.
- 2.
- 3.
- 4.

**Social:**

What activities make life meaningful for your son or daughter?

- 1.
- 2.
- 3.
- 4.

**Religious:**

Is there a special church or synagogue or person your son or daughter prefers for fellowship?

- 1.
- 2.
- 3.
- 4.

**Additional Considerations**

Advocate/Guardian: Who will look after, fight for, and be a friend to your son or daughter? (List 3-4 options.)

Trustee(s): Who do you trust to manage your son or daughter's supplementary funds? (List 3-4 options.)

## **ABCs of SSI**

### **Part 1 of a continuing series**

By Neal A. Winston

*The SSI program can be very difficult to understand for parents of children with disabilities. Last month's Special Needs Alliance column discussed why Harry and Sally's son Bill, who was eligible for Supplemental Security Income (SSI), could use a Special Needs Trust. This month, we will describe the SSI program in more detail with examples of how it might apply to your own family.*

Due to parental assets and income, many minor children with disabilities cannot become eligible for Social Security Income (SSI). Given this, why should you be interested in SSI eligibility details at this time? Once your child reaches the age of 18, only his or her own resources and income count. Planning for your child's future SSI eligibility should start now.

SSI is a "needs based" cash payment program, which means that not only must your child meet the Social Security definition of disability or blindness, but benefits will only be paid if resource and income limitations of the program are met. Many states also provide automatic Medicaid eligibility if any amount of SSI is paid. SSI is a different program than Social Security Disability Benefits, Child's Benefits, Disabled Adult Child's Benefits, or the other Social Security insurance programs based upon the family relationship of a child to a worker covered by Social Security. We will describe how to meet the disability definition and eligibility for the insurance benefit programs in future articles.

#### **Resource Limits**

Only limited resources are allowed for SSI eligibility. "Resources" are something that the recipient keeps from month to month and has an ownership interest in. There is a limit of \$2,000 for an individual for "countable" resources. Examples of resources include bank accounts, IRA's, savings bonds or stock, real estate and anything else that could be turned into cash, goods, or services used to support the person with special needs. Some resources that are "non-countable" against the \$2,000 limit include the principal residence, a vehicle, household furnishings and supplies, a burial contract and gravesite, assets in certain trusts and property or goods necessary for work.

#### **Income Limits**

Income must also be limited in order to receive SSI benefits. "Income" is something of value that the person receives in a particular month that can be used to provide support, food, clothing, or shelter. Income does not have to be cash. It can be a Social Security insurance benefit, room and board, trust distribution, insurance settlement, annuity payment, child support or alimony, earnings, or anything else that is received of value. Some types of income are not counted at all and include many governmental needs based benefits such as Emergency Aid or General Relief, Medicaid, Food Stamps and Section 8 housing.

A certain amount of income received each month that is countable is then excluded, meaning that it won't count against eligibility or reduce SSI benefits. A person is allowed to not count the first \$20 of regular income per month that is "unearned." Unearned means that it is any income not paid as earnings for work. "Earned" income is payment for work, and the first \$65 plus one-half of the remainder per month may also be excluded. A working child with disabilities under age 22 who is a student, and any recipient with work related expenses or in a special approved work program, is allowed an additional earned income exemption. If a person does not fully spend or use the income in the month received, the remainder becomes a resource the following month.

For example, 25-year-old Bill receives a Social Security Disabled Adult Child's Insurance Benefit of \$300 per month through his disabled father's own Social Security record. Bill also has a small bank account providing \$10 in monthly interest, receives Food Stamps, and has a job in which he

grosses \$200 per month. His “countable” income for SSI purposes is \$280 from the Social Security (\$300-\$20.), \$10. from the interest, \$0 for Food Stamps, and \$67.50 from the work earnings (\$200-\$65= \$135/2 = \$67.50). Bill’s total countable income for SSI would be \$357.50.

### **Parent’s Assets and Income Count**

Resources and income belonging to parents who live in the same household of a child under age 18 are also counted against the child’s SSI eligibility. This is called income and resource “deeming.” Some income that the parents receive does not apply to the calculation and allowances that are given for the parents and other non-disabled children. Examples of non-countable income include other public needs based benefits, foster child payments, housing assistance and the same earned and unearned income exemptions that the child with disabilities would receive. There is a special exemption— a “waiver”—in which all of the income and resources of the parents of a minor would not be counted if the child could otherwise qualify to be institutionalized except for the extraordinary efforts of the parents to keep the child at home.

As an example of how income deeming works, assume that Bill is now age 16 and he lives with his parents, Harry and Sally, and two younger siblings who are not disabled. Harry and Sally pay for all of Bill’s food, clothing and shelter costs from their own income. Harry receives \$3,000 in gross monthly work income. First subtract a credit of \$564 allocated to the other two children, leaving a balance of \$2,436. Next subtract the earned and unearned income exclusions (\$65 and \$20), and then exclude one-half of the remainder. This is calculated as  $\$2,436 - \$85 = \$2,351$ , and  $\$2,351/2 = \$1,175.50$ . Now subtract Harry and Sally’s parental living allowance of \$846 and the remainder of \$329.50 of Harry’s income is deemed to Bill as countable income for his SSI eligibility benefit amount calculation.

### **SSI Benefit Amount**

The actual SSI monthly benefit is calculated by subtracting countable income from a benefit level category that differs depending on the “living arrangement” that the eligible person lives in. For example, in 2004, the monthly full “federal benefit rate” (FBR) for a disabled or blind person “living alone” or proportionally “sharing” living expenses is \$564. It is \$376 if the person is “living in the household of another,” whereas this category applies to most children with disabilities who live in their parent’s home with the parents fully providing the child’s maintenance needs. Most states “supplement” the federal benefit rate by varying amounts depending on the living arrangement.

In Bill’s case, by using the income example above with countable income of \$329.50, his federal SSI benefit would be \$46.50 ( $\$376 - \$329.50$ ). What would happen if upon reaching age 18 Bill decided that he would pay his proportionate share of his own maintenance costs from his SSI benefit? He would be entitled to a monthly benefit of \$564 from the “shared living” category. Since parental deeming no longer applies because Bill has reached age 18, he would receive the full benefit payment without reductions caused by counting his parent’s income. However, he would also have to show that he reasonably paid his share of household expenses, or have his benefit reduced due to “in-kind” income from the parents.

## **Some income that the parents receive does not apply to the calculation and allowances that are given for the parents and other non-disabled children.**

### **In-kind Income**

“In-kind” income is a good or service of value provided by another party for the benefit of the SSI eligible person. For example, it might be direct payment on behalf of the SSI recipient for medical or education services, shelter costs, transportation, clothing, rent, household goods, a vehicle, or food. Provision of food, clothing, or shelter is called “in-kind support and maintenance” or ISM. If the payment is not for ISM, it will not reduce or otherwise affect the monthly SSI benefit. If ISM payments are made on behalf of a recipient, the SSI benefit in the full FBR categories will be reduced dollar for dollar up to one-third of the current full FBR, or up to \$188 per month.

The maximum ISM reduction is called the Presumed Maximum Value (PMV). The recipient's SSI will only be reduced by the lesser of the actual ISM or the PMV. The actual PMV reduction from a monthly benefit is \$208 because the \$20 unearned monthly exclusion is added to the one-third FBR of \$188. Therefore, if the ISM were more than \$208 per month, the reduction would be capped at \$208. For those SSI recipients who are already in the reduced "living in the household of another" category, the PMV would never apply and their benefits would not be reduced further by receiving ISM because they have already received the maximum one-third reduction of the federal benefit.

For example, 16-year-old Bill's parents buy him \$150 of clothing. Since he is already in the "living in the household of another" category, no further benefit reduction due to receiving the clothing would apply. Suppose that in February 2004, Bill is now 25 years old and is in the unreduced "shared living" category in his parent's home and receives \$100 in subsidized rent, a used \$300 computer and a \$50 bus pass from Harry and Sally. Only the rent will count as ISM, and after his SSI benefit is reduced by \$100, he will receive \$464, (\$564-\$100.). Then, in March 2004, Bill's grandfather dies and leaves \$100,000 in a special needs trust for Bill's benefit. Bill moves into an apartment in a special needs supported complex, and the trust directly pays his \$600 per month rent and utilities. He pays for his own food. His benefit will only be reduced by the PMV maximum of \$208. Bill will receive a SSI benefit of \$356 (\$564-\$208 = \$356).

### **Gifts May Cause Disqualification**

Beginning in December 1999, gifts of countable resources for less than market value by or on behalf of a recipient will cause a period of ineligibility for SSI. Some gifts are excluded from the penalty, such as gifting a home to a disabled child or sibling co-owner, or gifting cash assets to another person with disabilities. Transfers of property into a special needs trust with certain clauses, including pay back of any Medicaid used upon the recipient's death, will not cause a disqualification period. If the resource is non-countable for eligibility, and the purpose of gifting it is not to create or keep eligibility, then the gift will also not cause a disqualification period.

If a disqualifying gift is made, SSI will be suspended one month for the equivalent of one month's SSI benefits gifted away up to a maximum of 36 months. For example, Bill receives a \$10,000 inheritance and gifts it to his brother. If his combined federal and state supplement SSI benefit rates total \$600 per month, his disqualification would be for about seventeen months ( $\$10,000/\$600= 16.7$ ). If the gifted inheritance were \$30,000, the disqualification period would be 36 months from the month of the gift. If all or part of the inheritance was returned to him, the disqualification period would be accordingly reduced.

### **Where To Get Help**

Where can you get help with your own situation? Many individuals turn to the Social Security Administration, which is generally quite helpful in providing information. Nevertheless, agency interpretations can have some discretion involved, and therefore vary from person to person under similar situations and require representative advocacy. The SSA uses an operating manual called the Program Operation Manual System (POMS), which you can access on the Internet by going to [www.socialsecurity.gov](http://www.socialsecurity.gov). On the right-hand side of the home page under Resources, go to Our Program Rules, and then the Program Operations Manual System reference. From there check out the table of contents, and then the Supplemental Security Income (SSI) section. The complete POMS is over 65,000 pages long in its written form, and the details in this manual could be more than you wish to get involved in.

One source of professional help is the Special Needs Alliance. Knowledge of certain aspects of the program is integral to their work. The SNA website is [www.specialneedsalliance.com](http://www.specialneedsalliance.com), or you can call for a list of participating attorneys at 1-877-572-8472.

*Attorney Winston practices Elder Law in Somerville, Massachusetts in the firm of Moschella & Winston, LLP. He has widely counselled clients, lectured, written articles and books, trained attorneys, and been involved in legislative actions since the SSI program was created in 1973.*



## Finding More Funding for Your Child's Special Needs Trust

By Renée Colwill Lovelace, mba, jd, cea

A special needs trust (SNT) is a wonderful gift to a child with special needs, however, there is much more that parents and other benefactors can do.

There are two basic funding principles: (1) use what you have wisely, and (2) be creative in searching for more funds. The three phases of funding help attain the set goals: (1) preparing the SNT and special needs plan to leverage existing resources, (2) ensuring that resources are properly directed into the SNT, and (3) looking for additional funding sources.

### Mapping the events that alter public benefits is a key step to finding more funds by not wasting funds or opportunities.

#### Phase I: Prepare the SNT and Plan

An SNT and special needs plan with serious flaws may never have enough funds. The SNT can be much like a bucket with holes in the bottom. The best way to secure more funds for the SNT is often by preventing waste of what the family already has.

**Find the Right Attorney.** Special needs planning is not yet a standardized area of law. The attorney's knowledge base will make a big difference in identifying resources and strategies to leverage family funds and find more funding. The most experienced attorneys will often be those who have written or spoken about SNTs to other attorneys and professionals.

**Focus on the SNT Beneficiary First.** Focus first on the individual's likely future needs, such as employment and housing options, medical or assistance needs, and personal and social needs. One mental health professional noted that most individuals with disabilities are no longer satisfied with minimal activities in their lives but, instead, want a house, a car, a job, and a date on Saturday night.

Almost everyone will need housing, transportation, activities, and a social structure. For many, employment is a goal. But employment brings the risk of lost benefits, by losing the quantitatively-determined "disabled" label for Social Security Disability Insurance (SSD) or Supplemental Security Income (SSI), by building the individual's own Social Security work credits, or by hitting the SSI income limit. Lost benefits usually reduce funds available for the SNT.

**Examine Existing Resources.** There are three primary types of resources, each of which supports the others: paper (the planning), people (individual with special needs, family, benefactors, advocates, professional providers), and money. Careful planning with realistic reliance on the people resources is likely to leverage money resources, keeping more funds for the SNT. But it is also important to plan to protect the irreplaceable people resources.

**Develop a Road Map.** It is important to know what types of public benefits the individual beneficiary is likely to receive, and if and how those benefits are impacted by changes throughout time. Such profiles and plans may be developed in discussions and informal assessments, or by written reports.

SSD and SSI benefits may change due to life events. Under age 18, parents' income and resources are often deemed to their child. Benefits such as SSI secured after age 18 can be disrupted later by a parent's retirement, disability, or death. An SSI or SSD recipient's eligibility is affected by how much they work. Trust distributions can cause the loss of SSI, as can marriage or divorce, in some cases.

Many of the changes in benefits eligibility surprise individuals. But the details and quirks of public benefits translate into significant funding sources. Mapping the events that alter public benefits is a key step to finding more funds by not wasting funds or opportunities.

**Select an Excellent Trustee.** A corporate trustee with extensive SNT administration experience is often a wise choice due to the paperwork, accounting records, investment requirements, and general risks that are involved.

**Select Good Trustee Appointers and Advisors.** Devoted family members who have authority to remove and replace corporate trustees and to advise trustees on appropriate distributions will help save funds by monitoring SNT distributions.

**Require SNT Annual Reports and Distribution Plans.** Just like budgeting, accounting, and auditing for a million-dollar business, it is important to have outside auditors and reporters who have a process for compiling information about the SNT that is, in turn, useful for creating or modifying a distribution plan. Without such a review, there is greater risk of losses to the trust value through disputes or loss of public benefits. Annual reports and distribution plans can make SNT dollars work harder for the benefit of the SNT beneficiary.

**For the parents of a special needs child, especially full-time caregivers or parents working outside the home, there are simply not enough hours—and there never will be.**

## **Phase II: Ensure That Funds Get to the Trust**

Good estate planning that directs one's property at death is the most important step to insure that funds make it to the SNT. But there are other important steps as well.

**Analyze Each Asset.** One way to analyze assets is to develop a grid with all assets listed, and then review the options for transferring each asset. For example, when an individual owns a house or a life estate outright, he or she may be entitled to disability tax exemptions from a variety of taxing authorities. Each element of reduced cost or money saved translates into more money staying in the SNT.

**Prepare for Pre-Death Transfers.** Pre-death incapacity is a major risk to SNT funding. When parents or grandparents need Medicaid, transfers for the benefit of an individual who meets the definition of disabled may be exempt from Medicaid transfer penalties. But if there are not powers of attorney that permit transfers to an SNT at that time, it is possible that there will be nothing left to fund the SNT at the parent's or grandparent's death. See more about this in Phase III.

**Protect Against Later-Life Losses.** Poor planning may result in the need for a guardianship for a parent or grandparent. Once subject to guardianship, funds can be depleted rapidly, like a melting block of ice. Prior to incapacity, there may also be times of waning capacity when an individual has poor judgment. This is the time when individuals are more susceptible to scams and other poor decisions that can rapidly—indeed, almost instantly—deplete their resources. Planning in advance can reduce many risks to those who may otherwise direct their funds to an SNT.

**Protect Against Daily Depletion from Disorganization: Get a Bookkeeper.** Working with a bookkeeper can be a very valuable investment. The paperwork one faces when there are family members with disabilities can be enormous. For the parents of a special needs child, especially full-time caregivers or parents working outside the home, there are simply not enough hours—and there never will be. Good bonded and insured bookkeepers are hard to find, but can produce a great return on investment.

### **Phase III: The Search for More Funding Sources**

Funding sources can be low-tech or complex. Consider the following options:

**File for SSI as Soon as Possible.** Parents often delay filing for SSI due to their then-current ability to pay expenses. But filing for SSI and having access to Medicaid-funded services can free up other funds for long-term planning or more life insurance. The SSI check (\$564 in 2004) will be reduced by one third if the child is still living at home, but parents may prevent this one third reduction by establishing rental or expense sharing arrangements.

**Charitable Planning.** IRS Revenue Ruling 2002-20 provides that a charitable remainder trust (CRT) can make payments to an SNT for an individual who qualifies as “financially disabled.” CRT payments can continue throughout the individual’s lifetime, creating a replenishment funding stream for the SNT.

**Retirement Funds.** Working with retirement funds and SNTs is challenging. When it is possible, consider swapping assets with other heirs; for example, leave the retirement benefits to the other children and put more of the cash assets in the SNT.

**Child Support.** Child support payments belong to the child; if those funds go into an SNT, the SNT is self-settled and must meet pay-back requirements under 42 U.S.C. § 1396p(d)(4)(A). Consider using child support for regular expenses and using the parent’s other funds to purchase more insurance on the parent’s life, or getting a court order to direct the funds to an SNT rather than to child support payments.

**Exempt Transfers of a House.** An individual’s house can be transferred to a qualifying person (meeting the disabled definition) or to a qualifying trust for that individual. A mother, father, grandmother, grandfather, or any other benefactor, can make a gift of their house without incurring a Medicaid transfer penalty by either a direct transfer from parents, under 42 U.S.C. § 1396p(c)(2)(A)(ii), or a transfer to an SNT from parents or others pursuant to 42 U.S.C. § 1396p(c)(2)(B)(iii) or (iv). There are many technical requirements, so find an attorney who has gone down this road before.

**Other Exempt Transfers.** As noted earlier, parents, grandparents, and other benefactors have the opportunity to make transfers that are exempt from Medicaid penalties at a time when they need long-term care themselves. This technique can generate significant funds for an SNT under appropriate circumstances, and many older relatives may want to consider this option. See 42 U.S.C. § 1396p(c)(2)(B)(iii) and (iv).

**Life Insurance Policies.** Many older individuals have multiple small life insurance policies that are time-consuming and sometimes costly to liquidate if that individual later needs to apply for Medicaid. It would, in most cases, be more practical to liquidate and transfer the proceeds earlier.

**Insurance on Multiple Lives.** It is especially helpful to insure the lives of multiple caregivers and advocates to generate funds that will help replace the personal services that such caregivers and advocates provide.

**Insurance Trusts.** Insurance trusts reduce the risk of losing an insurance policy if the person who is insured experiences medical events that result in his or her need for public benefits, or if the insured experiences serious financial difficulties. These events may result in the liquidation and loss of the insurance policy.

**Establish an SNT and Tell Family Members How to Direct Funds to It.** Many benefactors leave assets directly to individuals with serious disabilities. In order to have such funds end up in an SNT, consider establishing an SNT to be funded by others, and providing instructions to family members on how to use it. By establishing an SNT for use by other family members, not only will

some of the pre-designated funds end up in the SNT, but other family members may put the SNT higher on their distribution list once they know there is something they can do to help.

**No Perfect Guidance System.**

There is not an ideal guidance system to help parents and other benefactors do good special needs planning and seize all opportunities, so it helps to recognize the challenges that families face in trying to do good planning.

Much like the Serenity Prayer, we as parents and planners should do what we can, make peace with what we cannot do, and carefully focus on which is which. We usually cannot fix all the problems or fully fund all future possible needs. What we can do, however, is work at developing a great plan and, once that is done, put it aside with less anxiety and a clearer understanding of what to watch for in the future.

*Renée Lovelace is an attorney with offices in Austin and Dripping Springs, Texas. She works with personal injury settlement trusts, SNTs and planning, elder law, long-term care planning, and advising trustees on distribution plans for SNTs. She has a J.D. from the University of Texas, M.B.A. from the University of Chicago, and B.A. from Oral Roberts University. Her husband, Joe, a former trial lawyer, is the public policy consultant for NAMI Texas (National Alliance for the Mentally Ill). Renée and Joe live in Dripping Springs with their 11-year-old daughter, Jessica, and also have two grown sons, one of whom has serious mental illness but who is now working and living independently. Renée can be reached at [RCLovelace@aol.com](mailto:RCLovelace@aol.com).*

## **Tax Basics for Families with Special Needs**

By Richard A. Courtney, CELA

Families of children and adults with disabilities often require a variety of services in order to fully meet the needs of the person with disabilities, as well as the rest of the family. The financial resources available to pay for medical, caregiving and other needs must be found, and the providers must be engaged to render these services.

Many families have implemented a "special needs trust" for the benefit of the special needs child or adult, and such a trust will allow access to government health benefits for the person with disabilities that would otherwise be unavailable. Many families have also found it necessary to employ paid caregivers to provide care for the persons with disabilities and respite for the other family members. This article will briefly discuss the basic tax consequences of the two most common types of special needs trusts for persons with disabilities and the tax issues associated with the employment of an outside caregiver.

### **Third-Party and Self-Settled Special Needs Trusts**

The family of a child with disabilities should take particular care in the family estate planning to maximize the resources available to meet the needs of that child, even after the parent(s) or primary provider is gone. If the parent has no will or living trust, the state laws of inheritance will generally require that a portion of that parent's estate assets pass to the special needs child at the parent's death. If such inheritance exceeds the level of assets the child is allowed to have for Supplemental Security Income (SSI) or Medicaid eligibility (usually \$2,000), this inheritance will disqualify the child for these valuable benefits to pay for medical, therapeutic and support needs. Therefore, the parent of such a child should establish a "special needs trust" (SNT) in his/her will or living trust, or separate from the will or trust, and should provide in the will or living trust that any share passing to the child with a disability will instead pass to the SNT. The SNT will be an irrevocable trust after the parent's death. The designated trustee will then hold and disburse the trust funds for services and purposes on behalf of the disabled beneficiary in such a manner as to retain the beneficiary's eligibility for public benefits. At the death of the disabled beneficiary, the remaining trust assets will pass to those persons or charities designated by the parent in the SNT. This type SNT is often referred to as a "third-party" SNT because it is to be funded with assets (such as gifts, life insurance proceeds, inheritance distributions) from parents, grandparents or others, NOT with assets of the beneficiary.

On the other hand, a "self-settled" SNT is generally established by a parent, grandparent, legal guardian or court for the benefit of the person with disabilities, but is funded with assets owned by the disabled beneficiary. Such assets can include: a lawsuit settlement arising out of injuries to the disabled beneficiary; an inheritance, or a life insurance settlement that is to come directly to the beneficiary rather than to a third-party SNT. A lawsuit settlement for personal injuries is not subject to income tax when received, however, the interest income generated by investment of those funds (except in a structured settlement annuity purchased with such an award) will be subject to income tax.

### **Income Tax Treatment of Trusts**

One important aspect of a special needs trust is the income tax treatment of such a trust. Trusts that are required to pay income taxes directly from the trust must pay such taxes at higher rates than individuals. For instance, in 2003 a tax-paying trust reached the 38.6 percent top rate at \$9,350 of taxable income, while an individual reached the 35 percent top rate at \$311,950 of taxable income. Tax laws classify trusts created by individuals as either "grantor" trusts (which are not treated as separate taxable entities) or "non-grantor" trusts (which are taxable entities). All revocable trusts (that is, which can be revoked by the grantor) are grantor trusts. Many irrevocable trusts can also be grantor trusts based upon the powers and rights retained by the grantor in the trust. Section 671 of the Internal Revenue Code ("IRC 671") provides that where

the person establishing a trust ("grantor") is considered the owner of the trust assets, then the "items of income, deductions and credits" of the trust will be included in the grantor's personal income tax determinations. IRC Sections 673 through 677 describe certain powers over the trust assets or income that will result in treating the grantor as owner of the trust. Simply summarized, these include: a provision in the trust that any portion of the trust exceeding five percent of the trust will revert back to the grantor in the future (IRC 673); a power by the grantor to change the disposition of trust assets or income (IRC 674); power by the grantor to deal with the trust assets for less than full consideration or borrow from the trust without adequate collateral (IRC 675); power by the grantor to revoke the trust and re-vest trust assets in the grantor (IRC 676); and a power by the grantor to require distribution of trust income to the grantor or grantor's spouse or to purchase life insurance on the life of grantor or his/her spouse (IRC 677). These Internal Revenue Code sections also contain exceptions which can be used through careful drafting to change a grantor trust to a non-grantor trust.

There may be financial reasons to make a special needs trust either a grantor trust or a non-grantor trust. One reason to have a grantor SNT is to avoid having the trust pay taxes on the income of the trust at the higher trust rates. All of the trust income of a grantor self-settled SNT (whether paid out for the beneficiary's needs or not), along with the deductions for professional fees and expenses, will be passed along to the beneficiary for inclusion on his/her personal income tax return at the lower individual tax rate. This may be desirable if the distribution needs of the disabled beneficiary make it unlikely that the trust will distribute most or all of the income for the benefit of the beneficiary. The reason for this is that a trust may take a tax deduction for all income distributed out to or for a beneficiary, while there is no such deduction for income earned but not distributed by the trust. Conversely, where the trust is likely to distribute most or all of its income for the beneficiary's needs, it may be advisable for the trust to have non-grantor status so that it can take the deduction for such distributed income and the professional fees and expenses. The result may be little or no taxable income to the trust. The determination of whether grantor trust or non-grantor trust tax treatment will be better depends on the particular circumstances of each family. For this reason, an attorney with special needs trust and tax experience should be used to assure the proper results.

### **Estate Tax Treatment of Trusts**

The estate tax is a tax on the value of assets owned by a person at death after deduction of that person's debts (the "taxable estate"). Under current law, there is no federal tax on taxable estates of less than \$1.5 million in 2004 (increasing to unlimited value in 2010 and falling back to \$1 million in 2011). The beginning tax rate on estates is 37 percent and increases to a top rate of 48 percent on estates over \$2 million (2004). A person's estate includes the value of all assets transferred by that person by trust, to the extent that the deceased grantor retained certain interests or powers over the trust. Some of the interests or powers over trust assets that will generally result in the trust assets being included in the grantor's estate include: the right to income from or possession or enjoyment of the assets; the right to designate the persons who will possess or enjoy the trust property or income; and the right to use trust assets to pay legal obligations of support, such as the general support of the grantor's spouse or minor children. (These provisions are found in IRC 2033 – 2041.)

Depending on the particular family financial circumstances, it may be advantageous to structure a special needs trust so as to remove the trust assets from the grantor's or beneficiary's estate. For instance, a parent or grandparent with a taxable estate may wish to create an irrevocable third-party SNT for a child or grandchild with disabilities and transfer some of the grantor's assets into the trust while the grantor is still living. If the grantor does not retain any of the interests or rights over the trust property that would cause it to be included in the grantor's estate, this will remove those assets from the grantor's estate and reduce the estate tax at the grantor's death. A self-settled SNT will generally be included in the estate of the beneficiary, since it is funded with the beneficiary's assets. However, if the trust is drafted such that the beneficiary retains no interest in or control over the trust property (including the right to determine in the beneficiary's will who will get the remainder after the beneficiary's death), the funding of the trust may be considered a

completed gift to the remainder beneficiaries and not part of the primary beneficiary's estate for estate tax purposes. In any event, the family and attorney setting up a special needs trust must ensure that, if the size of the trust will create an estate tax liability, there will be sufficient funds available to pay the taxes within nine (9) months after death. It is particularly important for an attorney settling a lawsuit into a SNT to have the settlement funds paid to the attorney, as attorney for the SNT, and then deposit the funds directly into the trust. Payment of settlement funds to the client, who later deposits them into the SNT, may create undesirable gift tax problems.

### **Employment of a Caregiver**

Families of persons with disabilities frequently engage caregivers from outside the home to help care for the disabled family member and provide respite for the family from such responsibilities. Caregivers may be found through agencies, in which case the family will make a payment to the agency to cover the wages, taxes, insurance and benefits the agency provides to the attendant. However, outside caregivers not employed by an agency will often request payment for services in cash and will agree to pay their own insurance and taxes as "independent contractors". This is rarely the correct method. The determination of whether a caregiver is an independent contractor (who will be responsible for paying their own taxes) or an "employee" (for whom the employer must withhold and pay unemployment and income taxes) will depend on several factors, including: right of control by the employer over details of the work; whether the employee is engaged in a distinct licensed occupation or business; whether the employer supplies the tools and place of work for the caregiver; the length of time for which the person is employed; whether the employer can discharge the worker; the method of payment, whether by the time or by the job; and whether the work is part of the regular business of the employer. Numerous cases have considered such factors and have found domestic caregivers to be employees rather than independent contractors. In such an event, tax and unemployment agencies will require the employer or employer's estate to pay the income and unemployment taxes that were not withheld along with penalties for non-payment.\* Therefore, the parent (or SNT trustee) should (1) treat a regular caregiver as an employee and withhold the FICA and taxes required, and (2) take out worker's compensation insurance in case the worker is injured on the job. A CPA or payroll service can assist the parent or trustee with these processes.

Tending to these tax details in the proper manner will minimize taxes and prevent later difficulties over unpaid taxes.

*\*See Estate of Dulaney v. Mississippi Employment Security Commission, 805 So.2d 643 (Miss. 2002).*

*Richard A. Courtney is a Certified Elder Law Attorney in the Jackson, MS firm of Frascogna Courtney, PLLC. He is a member of the Trust and Probate Section of the American Bar Association and the National Academy of Elder Law Attorneys. His emphasis is in the areas of elder law, estate planning, Medicaid and public benefits, trusts, disability law, and general civil litigation. He is the father of an adult disabled daughter and is a member of the Cerebral Palsy Foundation of Mississippi, Inc. (Board of Directors) and the Alzheimer's Association—Middle Mississippi Chapter. He is an Adjunct Professor of Law at Mississippi College School of Law, and a founding member of the Special Needs Alliance, LLC, a nationwide alliance of disability and special needs planning attorneys ([www.specialneedsalliance.com](http://www.specialneedsalliance.com)).*