RUBIN
LAW A Professional
Corporation

Special Needs Legal & Future Planning

Buffalo Grove • Chicago • Old Orchard
www.rubinlaw.com • email@rubinlaw.com
847-279-7999 • Toll Free 866.To.Rubin

Open letter to my fellow parents of children & adults with special needs from

Brian Rubin, Attorney & Parent of a son with autism...

Dear Fellow Parents,

As parents of children with special needs, we have all learned that no one, other than ourselves, is going to look out for the interests, for the future, of our child with special needs. While all parents need to make legal and financial plans for the future (who will take care of our children, who will control their inheritance until they are a more mature age, and how may federal and Illinois Estate Tax impact the planning), we, as parents of children with special needs, must begin our planning sooner and must plan for a much longer time period. We also must take into consideration many more details, laws and government regulations.

While not "special parents" as some tell us we are, we and our children do have unique needs that must be addressed... now! We cannot afford to procrastinate. We do every day, that which must be done. We "play the cards that have been dealt to us." We don=t know when we may pass away due to accident or illness. We must provide for who shall care for our "special" child after our death. We all wish... no, pray, that our child with special needs will have a long, happy and enjoyable life... <u>BUT</u>... we wish, we pray that we live at least one day longer than our child does, and that we will not have to place the "obligation" or Aburden@ upon others. We hope, we pray, that we will always "be there" for our child. But, as difficult as it is to think about our dying before our child with special needs, we must! We have that obligation to our child with special needs, to our other children, to our chosen guardians, and to ourselves.

We as parents of children with disabilities also have a need, a duty, to educate, to involve our "chosen" guardians for our children, now! If something happened to us, would our chosen guardians be able to step in without losing a step, without stumbling... in to the world of "special education", including MDCs, IEPs, Due Process Hearings, Transition Planning, related services,

federal laws and regulations, state laws and regulations including school codes, etc.? Would they be able to step in to the world of Social Security Disability, Medicaid, ISPs, respite services, residential placement options, Supported or Sheltered Employment options, Developmental Training Programs, In-Home Services, special medical needs, etc.? Does this mean that they must accompany us and participate at every event… every meeting? Obviously not, but you should brief them periodically as to "what is going on", "what you would like to be going on", and "where you see your child in the future". That is, they should be made aware of your "future plans". This all can be done face to face, but most of us prefer to reduce our thoughts, goals, wishes, desires, fears, concerns, aspirations, to writing, in a letter... a long letter, that you will be periodically updating. Often such a “letter” is referred to as a “Letter of Intent”. Our clients are provided a form. It is provided only as a guide and I always welcome suggestions on how to improve upon it. If you would like a copy, email me at brian@rubinlawcorp.com.

We also must remember, that while the "job" of the guardian for our "healthy" children stops at age eighteen, we are asking our chosen guardians for our child with special needs to accept a "lifelong" job.

Estate planning for parents such as ourselves is, as you can see, regretfully a very complex process. In order to provide for our "special needs" child=s financial security, to assure that our child remains qualified or able to qualify in the future for government benefits such as S.S.I. and Medicaid, and to protect any inheritance or gift from claims of the government for reimbursement for benefits provided to our child prior to our death or receipt of the gift, we must properly plan... now, and plan differently than other parents who are not in our situation. We must also consider in our plans the protection of any inheritance or gift from third parties, such as siblings, grandparents, aunts, uncles and friends, even those with the best of intentions.

The facts are that in Illinois, as is the case in most states, without proper wills and trusts, our children with special needs may inherit property or receive gifts only to be then disqualified from receiving government benefits. Additionally, without proper planning and drafting of estate plan documents, the government may claim reimbursement from the child’s inheritance or gift for benefits provided to our child prior to our death or receipt of such a gift. This result is true even with "traditional" family trusts with "spendthrift" provisions that many attorneys use for all parents. One of the primary objectives in estate planning for parents of a child with special needs is to assure that the child remains qualified and eligible for government entitlement programs, while protecting the family's assets, and the child's inheritance, from seizure by the government as "reimbursement."

The reality of our situation is... the bad news is... that the Illinois Appellate Court in 1982 held that interests of our children, even if maintained in a traditional family "spendthrift" trust created or

established in our wills or in living/revocable trusts, are to be considered assets, resources of our child and the State of Illinois would be entitled to recover all of the money it may have provided for food, clothing, residential care, medical care, etc. of our child from the trust fund, from the inheritance left for our child with special needs.

In the "dark ages" of planning for individuals with disabilities, it was often recommended by attorneys unfamiliar with (or worse, with some knowledge of) the area, to either disinherit the child (leaving the child dependent upon government programs, if any, and regardless of how inadequate or insufficient the government programs may be) and/or to leave that child's inheritance to the other children, other relatives, or friends. The intention would be that these people would be "morally obligated" to use those funds to supplement government benefits received, if any, by or for the benefit of the child with special needs. That advice is outdated. It is, in most cases, dangerous... bad advice.

First, as parents we have had to deal with government rules, regulations, and personnel, all of our child's life. We are not ready to abandon our child and rely upon the government to provide the level of care that we would desire or provide if we were alive. Second, if we rely upon the "moral obligation" concept, we have no assurance that the funds will be used for our child's benefit. There is no legal obligation to use the funds for the child. If there was such a legal obligation, the government could reach the funds, and disqualify our child from S.S.I. and Medicaid benefits. Third, with the "moral obligation" method, the funds are the exclusive property of the recipient, and can be reached by the recipient's creditors. Fourth, the recipient may have their own financial needs (such as their own children's college education) and "dip" into our child's inheritance, with the best of intentions to repay the amounts, though never in a position to do so. Fifth, if our trusted recipient places these funds in a joint account with their spouse, our child's inheritance may then be considered marital property. In a recipient's divorce, our child's money could be distributed to an ex-spouse of the recipient (with no such desire or inclination to honor "moral obligations"). Lastly, if the recipient passed away, who would receive the "moral obligation" inheritance, and would they have the same commitment to our child?

The good news is that since 1982, Illinois Appellate and Supreme Court case decisions have provided us a viable alternative. A special form of a Trust, a "Supplemental Discretionary Needs Trust," has become the appropriate and preferred estate planning document for parents such as ourselves. The Courts in Illinois have told us that if the Trust language is clear that the parents' intention, their express purpose in establishing the Trust, was to provide a source of funds to be available only to the extent that the government was unwilling or unable to so provide such funds; to provide funds only as a supplement to government funds, not in lieu of or in place of such funds; so that the Trust would be honored in Illinois... the "reserve fund" inheritance would be protected in Illinois.

The share of the estate of the child with disabilities (when both parents pass away) is maintained in a "special" Trust with very precise language, developed over the past decade from Illinois court decisions, and, in Illinois, allowable by a state law (Public Act 87-311), effective September 6, 1991. Public Act 87-311 incorporates and approves and/or ratified the last decade of Illinois court decisions. Public Act 87-311, in effect, encourages families to avail themselves of, to use, Supplemental Discretionary Trusts. Public Act 87-311 represents sound public policy and is clearly intended to "protect" Supplemental Discretionary Trusts by statute or law, without the necessity of relying on the existing court cases, always subject to judicial interpretation and based on particular facts. But this law could be changed, again! We as parents must "keep an eye" on our state legislators in Springfield, to make sure they don't "take away" the protection, the "peace of mind" provided to parents of children with disabilities by Public Act 87-311!

The Illinois law therefore, now provides that a discretionary trust established for the benefit of an individual who has a disability that substantially impairs the individual's ability to provide for his or her own care or custody and constitutes a substantial handicap, shall not be liable to pay or reimburse the State (and by current regulations, the Social Security Administration), or any public agency for benefits received. The Illinois law also provides that property, goods and services purchased or owned by such a trust for and or used by or consumed by the disabled beneficiary, are not to be considered assets of the beneficiary. The state's Mental Health & Developmental Disabilities Code was also changed by Public Act 87-311 to honor the terms of special needs trusts, if the trust is established, drafted, and maintained in accordance with the provisions of the Public Act. Too, too often we find Trusts drafted by Attorneys, “labeled” Special Needs Trusts, which do not qualify under the Statute, or do not comply with the Social Security Administration rules for such Trusts, called POMs. Too, too often we find that Attorneys draft such Special Needs Trusts, but fail to advise families when the applicable federal or state rules change.

On August 10, 1993, President Clinton signed into law what is commonly referred to as OBRA-93. Buried in this voluminous document are provisions which in certain circumstances, create new opportunities, for parents like us, to properly and adequately plan for the future care of our "special" child. The provisions allow for a second form of a Special Needs Trust to receive “P.I.” or Medical Malpractice Settlements, or inheritances left to our child with Special Needs, directly… and not in a Special Needs Trust… or if the child has assets in their own name… to “correct” or “save” the situation. So, as of January 1, 1996, a personal injury settlement awarded to our child with special needs, may also be protected in a trust, while still maintaining government benefits, and while Aoutside@ the reach of the government for reimbursement during the life of our disabled child! If the settlement is left in a Guardianship Account or in the child’s name… they would lose all such government benefits. It wasn’t until 1995 (effective 1/1/96) that Illinois amended the Special Needs Trust Law to incorporate the Federal 1993 changes. This second form of a Special Needs Trust, the

"OBRA 93" Trust, has many, many "drawbacks"… and would never be our first choice… but it is there as a tool to be used if such a situation occurs… and the Attorney should be aware and make you aware of its availability.

Then, again, buried in the Foster Care Act of 1999, new rules on Special Needs Trusts were established (effective 1/1/00). Simply stated, we can still use Discretionary Supplemental Needs Trusts, but we must do so in compliance with the ever changing laws, regulations, and administrative rules of our governments (federal and state) and Agencies like Social Security and Public Aid.

A ASpecial Needs Trust@ should also be used to receive Achild support@ payments awarded through a divorce proceeding in order not to disqualify the child from SSI, Medicaid, or other government benefits upon the child attaining age 18! However, the use of the Special Needs Trust must be by Court Order and not simply voluntarily. Further, in 2008, SSA national policy changed, and the Child Support must now be paid to a specific kind of a Special Needs Trust, a d4A, or First Party OBRA 93 Pay Back Trust.

The "Supplemental Discretionary Trust", in deference to a "Basic Support Trust," allows the child's inheritance to supplement, not supplant, government benefits. None of us wish to "trade" our dollars for the government's dollars. Rather, we want our dollars to be in addition to the government's dollars. The "Supplemental Discretionary Trust" assets are not intended to provide for basic support such as food, clothing, and shelter, unless government benefits are no longer available or are inadequate or insufficient for such purposes. The Trust may be used to enrich our child's life and make it more enjoyable. The Trust may provide recreational and vacation opportunities. The Trust may provide and pay for the expenses of a traveling companion. The Trustee may be authorized to provide resources to make our child's life as pleasant, comfortable, and happy as feasible.

The Trustee may be authorized to procure more sophisticated medical and/or dental treatment than may otherwise be available. The Trustee may also be authorized to seek private rehabilitative, social services and educational training. The Trust may also foster maintaining contact with siblings and other family members by authorizing the use of funds for transportation costs.

The Supplemental Discretionary Trust may also allow and/or provide for the "endowment" of or simply cash contributions to the organization or related foundation which is providing or which will provide in the future, the residential "home" for our "special needs" child, in order to assure the financial viability of that "home". Likewise, the support may be for the organization providing job skills and employment opportunities.

This special form of a trust, <u>if carefully drafted</u> by an attorney experienced (and up to date with the constantly changing laws and regulations such as OBRA-93 and the 1999 Foster Care Act, as well as SSA POMs) in planning for families of individuals - children and adults - with disabilities, may provide benefits and/or funds to the individuals with whom our child shall be living, to ease the financial and emotional burden placed upon them. This may include providing for additions to a home, a loan for a new home, domestic help, additional furniture, a special or modified van, medical equipment, etc. The Trust may authorize the "conversion" of your residence into a group home.

In addition to appropriate language in our Wills and Trusts, we must properly use Durable Powers of Attorney for Property and for Health Care. We must become familiar with the laws concerning "guardianship of an adult disabled person". We must also attempt to educate our "chosen" people, who will act as Custodial Guardians and Trustees about the relevant laws, regulations, programs and entitlements affecting or benefiting our child with special needs, as well as about our "plans" and desires, including our "estate plans." We must consider the school district, "residential alternatives", Special Recreation Association, religious programs available to individuals with disabilities and vocational or workshop opportunities available in the vicinity of our chosen custodial guardians.

We must also convince grandparents and other relatives that they are not doing their "special needs" grandchild or relative any favor by treating them the same as other beneficiaries in their own Wills and Trusts, but that any such "inclusion" should be to yourself, as parent(s), and that you shall provide for your child, or if both parents are not living, then to leave the "inheritance" to the Supplemental Discretionary Trust that you have created for such purpose.

There are still many, many other "special" objectives and considerations that I have not mentioned, that we, as parents of children with special needs, must consider in our "future" planning, that other parents need not.

My wife, Linda, and I have realized that being parents of a child with special needs has allowed us to more clearly and appropriately set our priorities and to appreciate what really is important in life, and... what is really not so important. But often the planning for parents in our situation is so understandably concerned and directed for the child with special needs, that appropriate planning for our other children, which in itself is so important to our children with special needs, is neglected. It should not be, for our "special" child will be "looking to" his or her siblings long after we are both gone.

Linda and I are blessed with three wonderful children, one of whom, Mitchell, is developmentally disabled. Mitch is blessed with an understanding and devoted older sister (assistant Mom), Nicole, and with a loving little brother and friend, Benji. I refer to Benji as Mitch's "little/big" brother. Mitch

also is blessed with Nicole's husband, Brad, "super son-in-law", who has become an integral part of Mitchell's life.

We, as parents of children with special needs pass through many stages of "adaptation". We first simply try to survive, that is, we attempt to keep going when we are feeling completely helpless because something totally out of our control has taken away, or at least significantly altered, our dreams, hopes and our child's equal chance at life. We then begin searching. We ask, "What's wrong with my child and can it be fixed"? We ask further, "What does this mean for my life"? We then enter the stage of "settling in" and shift our frame of mind from "coping" to "adapting". We begin letting go of unrealistic expectations for our child and for ourselves as parents, realizing that nobody's perfect. The next stage is "separating", which begins at birth, with each nudge toward independence. Our children with special needs often require extra-protection beyond the age where natural "letting" go usually occurs, creating special issues for us as parents. Proceeding through these stages can be chaotic and complex. We as parents of children with disabilities do not have the luxury to procrastinate. We must plan for the "future", now.

Brian Rubin

OUR FIRM'S & OUR FAMILY'S MISSION:

Special Needs Legal and Future Planning, with compassion and understanding, in order to guide our fellow families of children and adults with intellectual disabilities, developmental disabilities, and/or mental illness, down the "road to peace of mind".