

RUBIN

LAW

A Professional Corporation

Special Needs Legal & Future Planning

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What we do:

- **Special Needs Trust(s)**
- **Government Benefits Planning (Medicaid/SSI/Medicare/SSDI)**
- **Estate & Estate Tax Planning - Wills & Trusts**
- **Guardianship & Alternatives**
- **Powers of Attorney**
- **Letters of Intent**
- **Navigating the Illinois "MAZE" of children & adult services**
- **Estate, Probate, & Trust Administration**
- **Consulting on Special Needs Family Divorces**
- **Consulting on Special Needs Med-Mal/PI Settlements**
- **many related matters**

Attorneys & Staff

Attorney Brian Rubin, the founder of Rubin Law, a former IRS Agent and former IRS Estate Tax Attorney, has been a practicing attorney in private practice since 1978. He is the parent of three children, one of whom, Mitchell, has Autism. Brian's law practice, since 1982, when Mitchell was one year old, has been dedicated to serving the legal and future planning needs of his fellow families of children and adults with intellectual disabilities, developmental disabilities, and/or mental illness. Brian has been elected as a Fellow of the American College of Trust and Estate Counsel (ACTEC), and has received the Martindale-Hubbell AV® Preeminent™ Rating. He is President (2017-2018) of the Special Needs Alliance, the national, non-profit, association of experienced special needs planning attorneys (membership is by invitation only), served on the Special Needs Law Section Steering Committee, of the National Academy of Elder Law Attorneys, was a Charter Member of the Academy of Special Needs Planners, and is a Faculty Member and Text Book Author for the Illinois Institute for Continuing Legal Education (IICLE) on the topic of special needs legal and future planning, as well as a Speaker for the American Bar Association and the Illinois State Bar Association on those topics. Brian is a Past Chairman of the State of Illinois Statewide Advisory Council on Developmental Disabilities, Immediate Past Chairman of the State of Illinois Autism Task Force (2005-2015) established by the Illinois Legislature in 2005, serves as a member of the State of Illinois Guardianship & Advocacy Commission, served on the State of Illinois Department of Human Services Office of Inspector General Quality Care Board, among many other State of Illinois Committees and Commissions. Brian is the Immediate Past President of The Arc of Illinois; has been a member of the Board of Directors of Clearbrook (an organization serving more than 8,000 individuals with intellectual and/or developmental disabilities, including his son, Mitchell) since 1989, is Immediate Past Chairman of the Board of Directors of the Special Leisure Services Foundation, the foundation supporting the Northwest Suburban Special Recreation Association (NWSRA), served as the founding Chairman of the Board of Directors of the Foundation of The Special Education District of Lake County (SEDOL Foundation), served on the Board of Directors of KESHET (Jewish Parents of Children with Special Needs), serves on the Advisory Council of Encompass (Encompass in partnership with Jewish Child & Family Services, Jewish United Fund, JVS Chicago, JCC Chicago, Keshet, and The Center for Enriched Living and Center for Independent Futures), served on the Board of Directors of Pact, Inc., now known as DayOne Pact, the Independent Service Coordination Agent for individuals with intellectual and/or developmental disabilities living in DuPage, Kane and Kendall Counties Illinois, as well as serves as Trustee of Special Needs Trusts, and serves as Guardian, and served on the Board of Directors of Northpointe Resources, also an agency serving individuals with intellectual and/or developmental disabilities. Brian feels the tremendous responsibility of not only being the parent of a child with special needs, but also as an attorney with the knowledge and ability to assist others in the appropriate special needs legal and future planning needed to secure the future of children and adults with special needs.

Attorney Benjamin (Benji) Rubin, Brian's youngest son, Mitchell's "little/big" brother, has been a member of the Law Firm since 2010. Benji graduated from the University of Illinois College of Law, Magna Cum Laude, received his undergraduate degree from Northwestern University, and his Graduate Law Degree, an LLM (Tax), with honors, also from Northwestern University. Benji is a member of the Academy of Special Needs Planners, a member, by invitation, of the Special Needs Alliance (the national not for profit association of special needs planning attorneys with membership by invitation only), is Vice Chairman of the American Bar Association Special Needs Planning Committee, serves as the President of SIBS (Supporting Illinois Brothers and Sisters), the Illinois chapter of the national Sibling Leadership Network, an organization of adult siblings of individuals with intellectual disabilities, developmental disabilities and/or mental illness. Benji is a member of the Board of Directors of The Arc of Illinois, is a member of the Clearbrook Associate Board, an organization serving more than 8,000 individuals with disabilities, including his brother, Mitchell, serves on the Board of Directors of DayOne PACT, the Independent Service Coordination Agent for individuals with intellectual and/or developmental disabilities living in DuPage, Kane and Kendall Counties Illinois, as well as serves as Trustee of Special Needs Trusts, and serves as Guardian, serves on the Board of Directors of the Foundation of The Special Education District of Lake County (SEDOL Foundation), serves on the Advisory Council of Encompass (Encompass in partnership with Jewish Child & Family Services, Jewish United Fund, JVS Chicago, JCC Chicago, Keshet, and The Center for Enriched Living and Center for Independent Futures). Benji is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE) on the topic of special needs planning, as well as a Speaker for the American Bar Association and the Illinois State Bar Association on those topics. Having Mitchell as a brother profoundly shaped who Benji is today, and thus the type of law he chose to practice. His personal experiences as a sibling offer a unique perspective into the responsibilities that come with caring for a sibling with special needs. Now as an adult, those sometimes present and future responsibilities he has regarding his brother's care are a concern that he shares with all brothers and sisters of individuals with special needs.

Attorney Judith (Judie) Smith, has been licensed to practice law in the State of Illinois since 1985. She has been associated with Brian Rubin since 1996. Judie's practice, since 1996, has been limited to special needs estate planning and administration for families of individuals with special needs. Judie has handled countless adult guardianship matters for clients in Cook, Lake, McHenry, DuPage and Kane Counties. Her courtroom experience includes preparation and court approval of Medicaid "Pay Back" Trusts (also referred to as "OBRA '93 Trusts" and/or "d4A Trusts", preparation and court approval of trust and estate budgets, as well as preparation and approval of trust and estate annual accountings and annual reports. Judie is a member of the Special Needs Alliance. Judie is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE).

Attorney Melanie Hoffman, has been licensed to practice law in the State of Illinois since 1993. She began her career with the Office of the Cook County Public Guardian, working on behalf of abused and neglected children, and subsequently working in the Disabled Adult Division, responsible for estate administration and guardianship matters. Melanie has been associated with Brian Rubin since 1995. Melanie's practice was limited to estate planning, estate administration and guardianship for families of individuals with special needs. Melanie is an affiliate member of the Special Needs Alliance. Melanie is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE).

Paralegal Jill Yonover, joined Rubin Law in 2017. Jill has an undergraduate degree from Northwestern University and a graduate degree from New York University.

Office Manager and Legal Assistant Nicole Rosenthal, Brian Rubin's daughter, and Benjamin's and Mitchell's "big sister" (and assistant mother) joined Rubin Law as office manager and legal assistant in 2001. Nicole's undergraduate degree is in nursing and is a Registered Nurse (RN/BSN). Nicole, as an older sibling, brings an unparalleled understanding of the day-to-day obstacles, and successes that her fellow families of individuals with special needs endure.

Legal Assistant Karen Muschkat, joined Rubin Law as a legal assistant in 2007. Karen has more than 20 years of extensive experience in the areas of estate planning & estate administration.

Legal Assistant Linda Rubin, Brian Rubin's wife, joined Rubin Law as a legal assistant in 2001. Linda, as Mitch's Mom, offers an experienced point of view as someone who has lived through all the trials & tribulations that fellow families of individuals with special needs weather.

Legal Assistant Carmen Cuzmanko, joined Rubin Law in 2015 as a legal assistant. Carmen is a parent of child with autism.

Mitchell Rubin, Brian Rubin's son, who has autism among other diagnosed special needs, also works at Rubin Law on Mondays, shredding documents and greeting clients, among other assigned tasks.



Brian Rubin — Mitchell Rubin — Benjamin Rubin

"Legal and future planning for our fellow Illinois families of individuals with special needs, including intellectual disabilities, developmental disabilities, physical disabilities, and/or mental illness, is not one thing we do, it's the only thing we do; it's not one area of our practice, it's our only area of practice."

Brian N. Rubin, Attorney & Parent

Benjamin A. Rubin, Attorney & Sibling

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... BUT... 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~~g~~ 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, regrettably 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 Special Needs Trust should also be used to receive child 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, if carefully drafted 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".

Resources for Siblings of People with Disabilities



Sibling Leadership Network: www.siblingleadership.org

The Sibling Leadership Network (SLN) provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.



Supporting Illinois Brothers & Sisters (SIBS) www.sibsnetwork.org

SIBS is the Illinois chapter of the national Sibling Leadership Network. The mission of SIBS is to provide support to siblings of people with disabilities in Illinois by connecting them with information, networking opportunities, and resources in order to enhance the quality of life for their entire families.



Sibling Support Project: www.siblingsupport.org

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

Connect with Siblings Online: There are a number of online, interactive closed communities for siblings at different ages to connect with each other for information and peer support. Hosted by The Sibling Support Project, these groups serve as a front-line resource for sibs, by sibs! Siblings can look on Facebook to request to be added to a group.



- ❖ **SibTeen**—for sibs who are teenagers <https://www.facebook.com/groups/SibNet/>
- ❖ **Sib20**—for siblings in their 20s <https://www.facebook.com/groups/Sib20/>
- ❖ **SibNet**—for adult siblings <https://www.facebook.com/groups/SibTeen/>

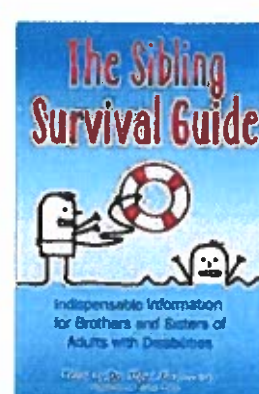
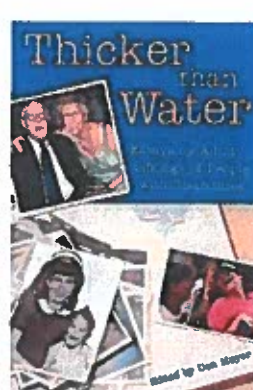
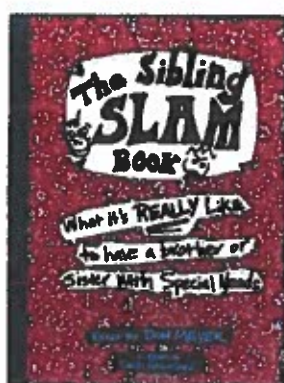
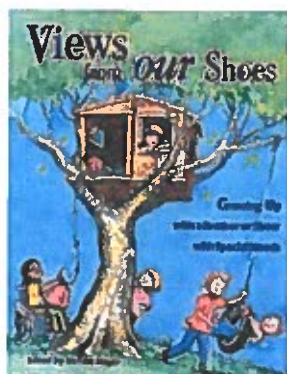


Sibshops are pedal-to-the-metal events where school-age brothers and sisters meet other sibs (usually for the first time), have fun, laugh, talk about the good and not-so-good parts of having a sib with special needs, play some great games, learn

something about the services their brothers and sister receive, and have some more fun. To find a Sibshop near you, visit: www.siblingsupport.org/about-sibshops/find-a-sibshop-near-you

Books for siblings of all ages:

There are lots of great books for siblings of all ages—check out the Sibling Support Project's Amazon Astore: <http://astore.amazon.com/thesibsuppro-20>. Here are a few good books for siblings:





Connect to us through our listserv
AdultSIBSNet—
<http://groups.yahoo.com/group/AdultSIBSNet>
AND
Facebook group -
SIBS Network

Or find us online at www.sibsnetwork.org.

Want to make a donation to S.I.B.S.?
Donate online via the S.I.B.S. "Causes"
page at <https://www.causes.com/sibs> or
send a check to:

c/o Nora Handler
3800 N. Lakeshore Drive #3E
Chicago, IL 60613

**For more info call 708-989-3619 or
email at Tara@sibsnetwork.org**

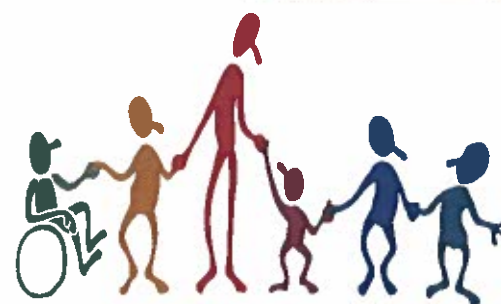


Sponsored in part by the Rehabilitation
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Supporting Illinois Brothers and Sisters
C/O of Nora Handler
3800 N. Lakeshore Drive #3E
Chicago, IL 60613



Supporting
Illinois
Brothers and
Sisters



"Stronger Together"

Supporting Illinois Brothers & Sisters, S.I.B.S.,
is a non-profit organization whose mission is to
provide support to siblings of people with
disabilities in Illinois by connecting them with
information, networking opportunities, and
resources in order to enhance the quality of life
for their entire families.

www.sibsnetwork.org



S.I.B.S. began with the dream of one sibling and grew into an established Illinois non-profit organization. While support and advocacy has focused on parents and people with disabilities, siblings have often been left out of the conversation. Siblings play an important role in the lives of their brothers and sisters with disabilities and have their own unique needs that should be discussed and addressed.

S.I.B.S. Purpose

S.I.B.S. provides support for siblings of individuals with disabilities in Illinois through various activities and resources designed to

- 1) provide opportunities for siblings to connect personally with one another;**
- 2) provide access to information of specific importance to siblings, including resources on future planning and community support;**
- 3) educate agencies, parents, and the public regarding the unique needs of siblings and the importance of sibling support; and**
- 4) provide siblings with the necessary tools to advocate with their brothers and sisters**

What We Do

We are an active and vibrant network that supports siblings of people with disabilities by connecting them with resources including:



Sibling Connections –

We connect Illinois siblings through social networking opportunities, educational events, and online resources such as Facebook and AdultSibsNet listserv.

Leadership, Outreach and Advocacy –

We promote leadership opportunities for siblings in the community. We welcome opportunities to present on sibling issues at conferences at the state, national, and international levels. We partner with organizations such as The Arc of Illinois and the Sibling Leadership Network.

Information and Education –

We provide siblings, families, and service providers with information and resources on topics of special importance to siblings, including future planning, navigating the service system in Illinois, and understanding our own needs as siblings.

Sibshop Facilitator Network –

We provide families of younger siblings with referrals to certified Sibshops in their communities, and connect individuals interested in becoming Sibshop facilitators with opportunities for training and certification.

SIBLING 
LEADERSHIP
NETWORK

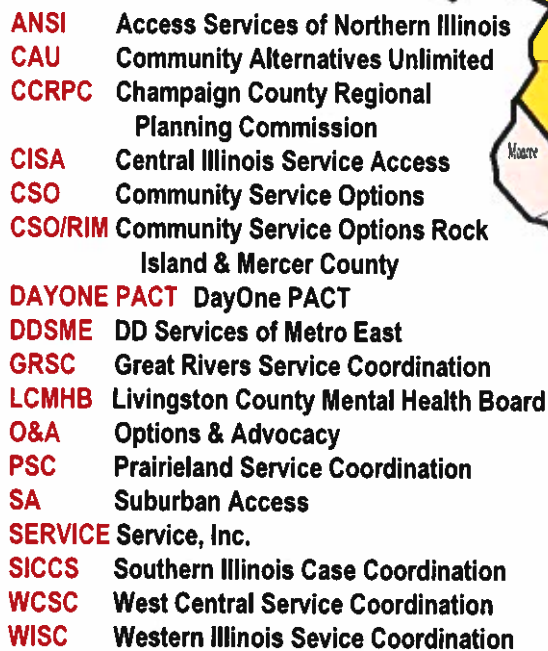
Core Values

As a chapter of the national Sibling Leadership Network (siblingleadership.org) we believe the following:

- Individuals with disabilities have the same rights as all members of society to dignity, respect and the opportunity to grow and to be productive members of their communities.
- Siblings of individuals with disabilities can have a powerful, positive impact on their siblings' experiences, and are uniquely positioned to help ensure their present and future care in partnership with service organizations and government.
- In promoting the rights of our brothers and sisters, and of all individuals with disabilities, we are committed to advocating for policies and services that meet their needs.
- Siblings can be of great support to one another to enhance both our lives and the lives of our siblings



Independent Service Coordination Agencies



ISC/PAS Agencies

1. **Access Services of Northern Illinois Developmental Disability Services**
7399 Forest Hills Rd, Loves Park, IL 61111; Phone: (815) 282-8824; Website: <http://www.accessni.com>
2. **Central Illinois Service Access (CISA) Developmental Disability Services**
101 Madigan Dr., Lincoln, IL 62656; Phone: (217) 732-4731; Fax: (217) 732-4870; Toll Free: (877) 437-9588
3. **Champaign Co Regional Planning Commission (CCRPC) Developmental Disability Services**
1776 E Washington St., Urbana, IL 61802, Phone: (217) 328-3313; Fax: (217) 328-2426
4. **Community Alternatives Unlimited (CAU) Developmental Disability Services**
8765 W Higgins Rd, 3rd Floor, Chicago, IL 60631; Phone: (773) 867-4000; Website: <http://www.cau.org>
5. **Community Service Options (CSO) Developmental Disability Services**
6845 S Western Ave., Chicago, IL 60636; Phone: (773) 471-4700; Fax: (773) 471-4770 ; Toll Free: (888) 276-4467; Website: <http://www.cso1.org>
6. **CSO/RIM Developmental Disability Services**
3601 Morton Dr., Suite 1 East Moline, IL 61244, Phone: (309) 278-0020
7. **DayOne PACT, Inc. Developmental Disability Services**
750 Warrenville Rd, Suite 300, Lisle, IL 60532; Phone: (630) 960-9700; Fax: (630) 960-9823; Toll Free: (800) 637-7181; Website: www.dayonepact.org
8. **Developmental Disabilities Services Metro East (DDSME) Developmental Disability Services**
900 Frank Scott Pkwy W, Suite 928, Belleville, IL 62223; Phone: (618) 236-7957; Fax: (618) 236-7925; Website: <http://www.ddsme.org>; St. Clair Phone No: (618) 236-7957; Madison Phone No: (618) 656-9663
9. **Great Rivers Service Coordination (GRSC) Developmental Disability Services**
901 W Morton Ave, PO Box 369, Jacksonville, IL 62650; Phone: (217) 243-2330; Fax: (217) 243-3971
10. **Livingston County Mental Health Board Developmental Disability Services**
310 E Torrance Ave, PO Box 504, Pontiac, IL 61764; Phone: (815) 844-7708
11. **Options & Advocacy McHenry County Developmental Disability Services**
365 Millennium Drive, Crystal Lake, IL 60012; Phone: (815) 477-4720; Toll Free: (888) 376-8828; Website: <http://www.optionandadvocacy.org>
12. **Prairieland Service Coordination Developmental Disability Services**
1670 S Taylorville Rd, Suite 220M, Decatur, IL 62521; Phone: (217) 362-6128; Fax: (217) 362-6129; Toll Free: (800) 866-8779
13. **Service, Inc. Developmental Disability Services**
1740 McDonough Street, Joliet, IL 60436; Phone: (815) 741-0800; Fax: (815) 741-1678; Toll Free: (800) 244-8008
14. **Southern Illinois Case Coordination Services (SICCS) Developmental Disability Services**
140 S Locust St, PO Box 588, Centralia, IL 62801; Phone: (618) 532-4300; Toll Free: (800) 828-7422
15. **Suburban Access, Inc. Developmental Disability Services**
900 Maple Ave, Homewood, IL 60430; Phone: (708) 799-9190; Toll Free: (800) 507-5057; Website: www.suburban-access.org
16. **West Central Service Coordination Developmental Disability Services**
957 West Washington Street, Pittsfield, IL 62363; Phone: (217) 285-5227; Toll Free: (888) 279-4812
17. **Western Illinois Service Coordination (WISC) Developmental Disability Services**
509 North Lafayette Street, Suite 203, Macomb, IL 61455; Phone: (309) 833-1621; Toll Free: (800) 699-3672; Website: <http://www.wiscmacomb.org>

From the Arc of Illinois

SO, YOU RECEIVED A LETTER THAT YOUR CHILD WAS SELECTED FROM THE PUNS LIST?

If you receive a letter informing you that your child has been selected to apply for services, **IMMEDIATELY** contact your Independent Service Coordination Agency (ISC). However, although you will be directed through the process from selection through initiation of services by your ISC Agency, there is another program through which you may also find assistance during this important time. **The Arc of Illinois' Ligas Family Advocate Program** has been implemented to help individuals with disabilities selected from PUNS due to the Ligas Consent Decree. Ligas Family Advocates (LFAs) are available to help you and the family members/caregivers/loved ones who are supporting you as you consider the life that you want, and how this funding can help you build that life. These LFAs are, themselves, all family members of individuals with disabilities who want to help others explore and understand new and creative ways to build the lives they truly desire in the community. Ligas Family Advocates can connect you with other individuals/families with similar goals or who share other commonalities.

The purpose of the Ligas Family Advocate Program is to provide family-to-family advocacy support for Ligas Class Members, individuals and their families who are selected through the Illinois Department of Human Services, Division of Developmental Disabilities (DDD) Prioritization of Urgency of Needs (PUNS) as a result of the Ligas Consent Decree. It is a place to get accurate information about options and so much more...We are here to help! **Please call 708-331-7370!** We will help you to understand ALL of the options available through both Home-Based Services and CILA options.

We know that some of you have been looking forward to this day for many years and have already made decisions about services and providers. Others still have questions and concerns and would like to access as much information and as many resources as possible before making decisions about how to best utilize this funding. For those selected we hope that this is a big step forward in achieving a full and fulfilling life. We look forward to meeting you and providing assistance along the way.

Brian Rubin, Immediate Past President of the Arc of Illinois

Benji Rubin, Member of the Board of Directors, the Arc of Illinois

PUBLIC NOTICE OF INTENT TO CHANGE CATEGORIES FOR THE PRIORITIZATION OF URGENCY OF NEED FOR SERVICES (PUNS) WAITING LIST

The Illinois Department of Human Services, through the Division of Developmental Disabilities, invites all comments on our proposed change to the categories currently used to place individuals with developmental and intellectual disabilities on the PUNS waiting list.

The purposes of the proposed changes are (1) to reduce confusion, (2) to increase transparency, and (3) to make the selection process more predictable for the individuals we serve and their families.

Currently, an individual can be placed into one of three categories on the PUNS list: Emergency (services needed immediately); Critical (services needed within 1 year); and Planning (services needed in 1 to 5 years). **The Department proposes to change from three categories into two: (1) "Seeking Services" and (2) "Planning for Services".** Feedback from our stakeholders identified several problems with the three current categories. First, we have heard that there is a lot of confusion regarding the differences between the "emergency" and "critical" categories, as they sound very similar. Second, despite the best efforts of the Division of Developmental Disabilities and the Independent Service Coordination Agencies, there were inconsistencies surrounding when an individual should be placed into the "emergency" or "critical" category. In many cases the designation was more art than science. Third, because there were certain criteria that received preferences in selection off of the PUNS list other than the length of time an individual was waiting for services, families told us it was very hard to predict and prepare for when their loved ones would be selected. Under the proposed change, instead of two confusing and competing categories of people seeking services, there will be one.

Now that we have several years of experience selecting individuals from the PUNS list and offering them the opportunity to enter waiver services, we feel that moving to two categories will allow a family to better and more accurately plan for their loved one's future. By moving to two categories, **individuals will be selected from the "Seeking Services" category by length of time on the PUNS list, where the clock for length of time begins calculating either from initial placement on the PUNS list (if enrollment in PUNS occurred after the individual's 18th birthday) or from the individual's 18th birthday (if enrollment in PUNS occurred before the individual's 18th birthday). The Division will continue to handle all situations that rise to the crisis level as it currently does, whether an individual is enrolled in PUNS or not.**

Families with loved ones currently on PUNS will not need to do anything. The Department will make certain everyone currently on the list as either "Emergency" or "Critical" gets moved over to "Seeking Services". Those individuals currently in "Planning" will automatically be moved to "Planning for Services." New individuals who choose to join the PUNS list will be added to the PUNS list by the date of their enrollment.

Please send all comments on this proposed change to DHS.DDDComments@illinois.gov no later than July 20, 2018.

Private OR Employer Group Health Insurance Policies

215 ILCS 5/356b)

Sec. 356b. (a) **This Section applies to the hospital and medical expense provisions of an accident or health insurance policy.**

(b) If a policy provides that coverage of a dependent person terminates upon attainment of the limiting age for dependent persons specified in the policy, the attainment of such limiting age does not operate to terminate the hospital and medical coverage of a person who, because of a disabling condition that occurred before attainment of the limiting age, is incapable of self-sustaining employment and is dependent on his or her parents or other care providers for lifetime care and supervision.

(c) For purposes of subsection (b), "dependent on other care providers" is defined as requiring a Community Integrated Living Arrangement, group home, supervised apartment, or other residential services licensed or certified by the Department of Human Services (as successor to the Department of Mental Health and Developmental Disabilities), the Department of Public Health, or the Department of Healthcare and Family Services (formerly Department of Public Aid).

(d) The insurer may inquire of the policyholder 2 months prior to attainment by a dependent of the limiting age set forth in the policy, or at any reasonable time thereafter, whether such dependent is in fact a person who has a disability and is dependent and, in the absence of proof submitted within 60 days of such inquiry that such dependent is a person who has a disability and is dependent may terminate coverage of such person at or after attainment of the limiting age. In the absence of such inquiry, coverage of any person who has a disability and is dependent shall continue through the term of such policy or any extension or renewal thereof.

(e) This amendatory Act of 1969 is applicable to policies issued or renewed more than 60 days after the effective date of this amendatory Act of 1969.

(Source: P.A. 99-143, eff. 7-27-15.)

(215 ILCS 5/367b)

Sec. 367b. (a) **This Section applies to the hospital and medical expense provisions of a group accident or health insurance policy.**

(b) If a policy provides that coverage of a dependent of an employee or other member of the covered group terminates upon attainment of the limiting age for dependent persons specified in the policy, the attainment of such limiting age does not operate to terminate the hospital and medical coverage of a person who, because of a disabling condition that occurred before attainment of the limiting age, is incapable of self-sustaining employment and is dependent on his or her parents or other care providers for lifetime care and supervision.

(c) For purposes of subsection (b), "dependent on other care providers" is defined as requiring a Community Integrated Living Arrangement, group home, supervised apartment, or other residential services licensed or certified by the Department of Human Services (as successor to the Department of Mental Health and Developmental Disabilities), the Department of Public Health, or the Department of Healthcare and Family Services (formerly Department of Public Aid).

(d) The insurer may inquire of the person insured 2 months prior to attainment by a dependent of the limiting age set forth in the policy, or at any reasonable time thereafter, whether such dependent is in fact a person who has a disability and is dependent and, in the absence of proof submitted within 31 days of such inquiry that such dependent is a person who has a disability and is dependent may terminate coverage of such person at or after attainment of the limiting age. In the absence of such inquiry, coverage of any person who has a disability and is dependent shall continue through the term of such policy or any extension or renewal.

(e) This amendatory Act of 1969 is applicable to policies issued or renewed more than 60 days after the effective date of this amendatory Act of 1969.

(Source: P.A. 99-143, eff. 7-27-15.)

Divorced? Child Support for Non-Minor Child

750 ILCS 5/513.5

(effective 1/1/16)

Support for a non-minor child with a disability.

(a) The court may award sums of money out of the property and income of either or both parties or the estate of a deceased parent, as equity may require, for the support of a child of the parties who has attained majority when the child is mentally or physically disabled and not otherwise emancipated. The sums awarded may be paid to one of the parents, to a trust created by the parties for the benefit of the non-minor child with a disability, or irrevocably to a special needs trust, established by the parties and for the sole benefit of the non-minor child with a disability, pursuant to subdivisions (d)(4)(A) or (d)(4)(C) of 42 U.S.C. 1396p, Section 15.1 of the Trusts and Trustees Act, and applicable provisions of the Social Security Administration Program Operating Manual System. An application for support for a non-minor disabled child may be made before or after the child has attained majority. Unless an application for educational expenses is made for a mentally or physically disabled child under Section 513, the disability that is the basis for the application for support must have arisen while the child was eligible for support under Section 505 or 513 of this Act.

(b) In making awards under this Section, or pursuant to a petition or motion to decrease, modify, or terminate any such award, the court shall consider all relevant factors that appear reasonable and necessary, including:

(1) the present and future financial resources of both parties to meet their needs, including, but not limited to, savings for retirement;

(2) the standard of living the child would have enjoyed had the marriage not been dissolved. The court may consider factors that are just and equitable;

(3) the financial resources of the child; and

(4) any financial or other resource provided to or for the child including, but not limited to, any Supplemental Security Income, any home-based support provided pursuant to the Home-Based Support Services Law for Mentally Disabled Adults, and any other State, federal, or local benefit available to the non-minor disabled child.

(c) As used in this Section:

A "disabled" individual means an individual who has a physical or mental impairment that substantially limits a major life activity, has a record of such an impairment, or is regarded as having such an impairment.

"Disability" means a mental or physical impairment that substantially limits a major life activity.

See other side...

Child support payments that are required to be paid by a parent in accordance with 750 ILCS 5/513.5 by Court order, may result in a reduction or the complete elimination of a child's SSI (Supplemental Security Income) benefit as well as the child's Medicaid, which provides the child's medical coverage, therapy, employment support, and home or residential support services needed for the appropriate support for that child with special needs, and the custodial parent.

Because many programs for individuals with special needs are only available to individuals who have Medicaid eligibility, *preserving this eligibility does more than just keep medical coverage in place. Therefore the child support that was intended to benefit the child may, without proper planning, result in unintended, detrimental consequences.* For a child age 18 or older one hundred percent (100%) minus \$20.00 of the child support payments ordered by Court, count as a reduction against SSI (see Social Security Administration's POMS SI 00830.420 C.1.).

However, Government benefits can be protected if the court order directs that child support payments are to be made to a "special version" of a Special Needs Trust for the sole benefit of that child, known as a self-settled special needs trust (also known as a 1st party, "pay-back", OBRA, d4A, or d4C special needs trust). Support payments to such a special needs trust do not displace SSI, nor jeopardize Medicaid and Medicaid Waiver programs, greatly benefitting both parents and the child. The Social Security Administration's Supplemental Security Income "rules" (POMS) provides the following example:

"A disabled SSI recipient over age 18 receives child support which is assigned by court order directly into the trust. Since the child support is the SSI recipient's income, the recipient is the grantor of the trust and the trust is a resource unless it meets an exception in SSI 01120.203. If the trust meets an exception and is not a resource, the child support is income unless it is irrevocably assigned to the trust, per SSI 01120.201 J.1.d. In this example, the court ordered the child support to be paid directly into the trust, so we consider it to be irrevocably assigned to the trust."

The relevant provision added in January 2009 to Social Security's POMS (Program Operating Manual System) at SI 01120.200G1d requiring 1st party Special Needs Trusts for this purpose, provides: "A legally assignable payment that is assigned to a trust is income for SSI purposes unless the assignment is irrevocable. For example child support paid directly to a trust as a result of a court order, are not income."

Again, for a child age 18 or older, one hundred percent (100%) minus \$20.00 of the child support payment counts as a reduction against SSI (see POMS SI 00830.420 C.1.); unless the court order provides that such support be paid irrevocably to an appropriate special needs trust.

In accordance with 750 ILCS 5/513.5.5, the court order shall provide that the sums awarded shall be paid "irrevocably to a special needs trust, established by the parties, and for the sole benefit of the non-minor child with a disability, pursuant to subdivisions (d)(4)(A) or (d)(4)(C) of 42 U.S.C. 1396p, Section 15.1 of the Trusts and Trustees Act, and applicable provisions of the Social Security Administration Program Operating Manual System."

EFFECT OF DISSOLUTION OF MARRIAGE

A. 755 ILCS 5/4-7(b) provides that upon dissolution of marriage or declaration of invalidity of marriage the testator revokes every legacy or interest or power of appointment given to or nomination to fiduciary office of the testator's former spouse **in a will executed before the entry of the judgment of dissolution of marriage** or declaration of invalidity of marriage and the will takes effect in the same manner as if the former spouse had died before the testator.

B. 760 ILCS 35/1 provides that judicial termination of the marriage of the settlor of a trust revokes every provision which is *revocable* by the settlor pertaining to the settlor's former spouse in a **trust instrument or amendment thereto executed by the settlor before the entry of the judgment of judicial termination of the settlor's marriage**, and any such trust shall be administered and construed as if the settlor's former spouse had died upon entry of the judgment of judicial termination of the settlor's marriage unless the judgment of judicial termination of marriage expressly provides otherwise. Under the Illinois Trust and Dissolutions of Marriage Act, 760 ILCS 35/1, upon a judicial termination of marriage of the settlor of a trust, every provision which is revocable by the settlor pertaining to the settlor's former spouse in a trust instrument or amendment which has been executed by the settlor before the entry of the judgment of judicial termination is revoked and the trust is to be administered and construed as if the settlor's former spouse had died upon entry of the judgment of judicial termination of the settlor's marriage. Under this statute a provision is considered "revocable by the settlor" if the settlor has the power at the time of entry of the judgment of judicial termination of marriage to "revoke, modify or amend said provision, either alone or in conjunction with any other person or person". Note that under this definition, if the settlor has reserved no such powers to revoke or amend the trust, i.e. under the terms of an irrevocable life insurance trust or gift trust, the dissolution of marriage would not affect the spouse's right to serve as trustee. The terms of settlement between the parties might include a specific provision whereby the spouse would resign as trustee and/or renounce all rights under the trust, and the order of dissolution might so reflect this agreement.

Specifically, **a special needs trust is irrevocable and the above statute does NOT apply to special needs trusts!**

C. Operation of law terminated the former spouse's status as beneficiary of the other **spouse's IRA**. *In re Estate of Davis*, 225 Ill.App.3d 998, 589 N.E.2d 154 (2nd Dist. 1992).

D. The Seventh Circuit in *Fox Valley & Vicinity Construction Workers Pension Fund v. Brown*, 897 F.2d 275 (7th Cir. 1990) held that because the parties signed a voluntary property settlement agreement that included an explicit mutual waiver of rights each had in other's pension plan, the Wife was not entitled to be a beneficiary of the interest the husband had in his qualified pension plan.

E. A waiver by the wife in a property settlement agreement of any interest in the husband's life insurance policy barred the ex-wife from collecting as a beneficiary. *Mutual Life Insurance Co. v. Juntanen*, 189 Ill.App.3d 224, 545 N.E.2d 224 (1st Dist. 1989).

F. Under the Illinois Trust and Dissolutions of Marriage Act, 760 ILCS 35/1, upon a judicial termination of marriage of the settlor of a trust, every provision which is revocable by the settlor pertaining to the

settlor's former spouse in a trust instrument or amendment which has been executed by the settlor before the entry of the judgment of judicial termination is revoked and the trust is to be administered and construed as if the settlor's former spouse had died upon entry of the judgment of judicial termination of the settlor's marriage. Under this statute a provision is considered "revocable by the settlor" if the settlor has the power at the time of entry of the judgment of judicial termination of marriage to "revoke, modify or amend said provision, either alone or in conjunction with any other person or person". Note that under this definition, if the settlor has reserved no such powers to revoke or amend the trust, i.e. under the terms of an irrevocable life insurance trust or gift trust, the dissolution of marriage would not affect the spouse's right to serve as trustee. The terms of settlement between the parties might include a specific provision whereby the spouse would resign as trustee and/or renounce all rights under the trust, and the order of dissolution might so reflect this agreement.

G. A revocable, non-amendable trust instrument may include a provision indicating that upon the termination of marriage all rights of the spouse designated therein, including the right to serve as trustee and as a beneficiary, would terminate.

H. There is no corresponding provision for termination of a former spouse's rights under a life insurance policy absent a specific change in the beneficiary designation or a specific termination of the former spouse's rights under the order of dissolution.

I. The United States Supreme Court and *Egelhoff ex-rel. Breiner*, 121 S.Ct. 1322 (S.Ct. 2001) held that ERISA overrode state statutes which provided for "revocation-on-divorce" of beneficiary designations under employer-provided life insurance and pension plans. Consequently, any change in beneficiary designation must be reflected in the order and implemented under ERISA standards.

PRE-DIVORCE PLANNING: While the statutory provisions noted above or the terms of an order of dissolution may cure or address beneficiary or fiduciary designations of a former spouse, these provisions only become effective upon the dissolution of marriage. During a period of separation or pending divorce, these designations are unaffected. Consequently, clients in such situations should carefully consider the terms of their wills or living trusts as well as other assets passing through titling, such as joint tenancy property, life insurance beneficiary designations, retirement plan beneficiary designations, annuity contracts and payable on death accounts.

Beneficiary designations on IRAs may be changed without spousal consent. However, ERISA qualified plans require spousal consent for beneficiary changes. A client may consider withdrawing from a qualified plan and transferring plan assets to an IRA if this option is available.

Irrevocable designations, such as under an irrevocable life insurance trust, may be reviewed to determine if a trustee or a designated third party has the ability to amend or modify the terms of the trust.

Joint tenancy accounts may be closed or joint tenancy assets severed.

Memorandum to clients regarding reporting of special needs trusts and ABLE Accounts to SSA and HFS

1. ***Report to SSA and HFS any Third Party Special Needs Trust, even if unfunded. Specifically state:***

"Exempt 3rd Party Special Needs Trust in accordance with 760 ILCS 5/15.1 (P.A. 89-205, eff. 1-1-96.), the Illinois Trusts and Trustees Act, and 405 ILCS 5/5-105, the Illinois Mental Health and Developmental Disabilities Code (P.A. 87-311; 88-380). SEE ATTACHED

2. ***Report to SSA and HFS any First Party Special Needs Trust. Specifically state:***

"Exempt 1st Party Special Needs Trust in accordance with 760 ILCS 5/15.1 (P.A. 89-205, eff. 1-1-96.), the Illinois Trusts and Trustees Act, and 405 ILCS 5/5-105, the Illinois Mental Health and Developmental Disabilities Code (P.A. 87-311; 88-380), and further, specifically pursuant to 42 U.S.C. Section 1396p(d)(4)(A), as amended by the Omnibus Reconciliation Act of 1993 (OBRA) and by Section 5007 of the 21st Century Cures Act entitled "Fairness in Medicaid Supplemental Needs Trusts, 305 ILCS 5/2.1a, and 89 Ill. Admin. Code, Ch. 1, Sec. 120.347." SEE ATTACHED

3. ***Report to SSA and HFS any ABLE Account. Specifically state:***

"Exempt ABLE Account in accordance with Public Law 113-295 ("The Tax Increase Prevention Act of 2014"), which established "The Stephen Beck, Jr., Achieving a Better Life Experience Act (ABLE Act)", enacted December 19, 2014.", and in accordance with Illinois Public Act 099-0145 (7-27-15), 15 ILCS 505/16.6". SEE ATTACHED

(760 ILCS 5/15.1) (from Ch. 17, par. 1685.1)

Sec. 15.1. Trust for a beneficiary with a disability. A discretionary trust 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 disability shall not be liable to pay or reimburse the State or any public agency for financial aid or services to the individual except to the extent the trust was created by the individual or trust property has been distributed directly to or is otherwise under the control of the individual, provided that such exception shall not apply to a trust created with the property of the individual with a disability or property within his or her control if the trust complies with Medicaid reimbursement requirements of federal law. Notwithstanding any other provisions to the contrary, a trust created with the property of the individual with a disability or property within his or her control shall be liable, after reimbursement of Medicaid expenditures, to the State for reimbursement of any other service charges outstanding at the death of the individual with a disability. Property, goods and services purchased or owned by a trust for and used or consumed by a beneficiary with a disability shall not be considered trust property distributed to or under the control of the beneficiary. A discretionary trust is one in which the trustee has discretionary power to determine distributions to be made under the trust.

(Source: P.A. 99-143, eff. 7-27-15.)

(405 ILCS 5/5-105) (from Ch. 91 1/2, par. 5-105)

Sec. 5-105. Each recipient of services provided directly or funded by the Department and the estate of that recipient is liable for the payment of sums representing charges for services to the recipient at a rate to be determined by the Department in accordance with this Act. **If a recipient is a beneficiary of a trust described in Section 15.1 of the Trusts and Trustees Act, the trust shall not be considered a part of the recipient's estate and shall not be subject to payment for services to the recipient under this Section except to the extent permitted under Section 15.1 of the Trusts and Trustees Act.**

If the recipient is unable to pay or if the estate of the recipient is insufficient, the responsible relatives are severally liable for the payment of those sums or for the balance due in case less than the amount prescribed under this Act has been paid. If the recipient is under the age of 18, the recipient and responsible relative shall be liable for medical costs on a case-by-case basis for services for the diagnosis and treatment of conditions other than that child's disabling condition. The liability shall be the lesser of the cost of medical care or the amount of responsible relative liability established by the Department under Section 5-116. Any person 18 through 21 years of age who is receiving services under the Education for All Handicapped Children Act of 1975 (Public Law 94-142) or that person's responsible relative shall only be liable for medical costs on a case-by-case basis for services for the diagnosis and treatment of conditions other than the person's disabling condition. The liability shall be the lesser of the cost of medical care or the amount of responsible relative liability established by the Department under Section 5-116. In the case of any person who has received residential services from the Department, whether directly from the Department or through a public or private agency or entity funded by the Department, the liability shall be the same

regardless of the source of services. The maximum services charges for each recipient assessed against responsible relatives collectively may not exceed financial liability determined from income in accordance with Section 5-116. Where the recipient is placed in a nursing home or other facility outside the Department, the Department may pay the actual cost of services in that facility and may collect reimbursement for the entire amount paid from the recipient or an amount not to exceed those amounts determined under Section 5-116 from responsible relatives according to their proportionate ability to contribute to those charges. The liability of each responsible relative for payment of services charges ceases when payments on the basis of financial ability have been made for a total of 12 years for any recipient, and any portion of that 12 year period during which a responsible relative has been determined by the Department to be financially unable to pay any services charges must be included in fixing the total period of liability. No child is liable under this Act for services to a parent. No spouse is liable under this Act for the services to the other spouse who wilfully failed to contribute to the spouse's support for a period of 5 years immediately preceding his or her admission. Any spouse claiming exemption because of wilful failure to support during any such 5 year period must furnish the Department with clear and convincing evidence substantiating the claim. No parent is liable under this Act for the services charges incurred by a child after the child reaches the age of majority. Nothing in this Section shall preclude the Department from applying federal benefits that are specifically provided for the care and treatment of a person with a disability toward the cost of care provided by a State facility or private agency.

(Source: P.A. 99-143, eff. 7-27-15.)

(15 ILCS 505/16.6)

Sec. 16.6. ABLE account program.

(a) As used in this Section:

"ABLE account" or "account" means an account established for the purpose of financing certain qualified expenses of eligible individuals as specifically provided for in this Section and authorized by Section 529A of the Internal Revenue Code.

"ABLE account plan" or "plan" means the savings account plan provided for in this Section.

"Account administrator" means the person selected by the State Treasurer to administer the daily operations of the ABLE account plan and provide marketing, recordkeeping, investment management, and other services for the plan.

"Aggregate account balance" means the amount in an account on a particular date or the fair market value of an account on a particular date.

"Beneficiary" means the ABLE account owner.

"Board" means the Illinois State Board of Investment.

"Contracting state" means a state without a qualified ABLE program which has entered into a contract with Illinois to provide residents of the contracting state access to a qualified ABLE program.

"Designated representative" means a person who is authorized to act on behalf of an account owner. An account owner is authorized to act on his or her own behalf unless the account owner is a minor or the account owner has been adjudicated to have a disability so that a guardian has been appointed. A designated representative acts in a fiduciary capacity to the account owner. The State Treasurer shall recognize a person as a designated representative without appointment by a court in the following order of priority:

- (1) The account owner's plenary guardian of the estate, or the account owner's limited guardian of financial or contractual matters. Any guardian acting in this capacity shall not be required to seek court approval for any ABLE qualified distributions.

- (2) The agent named by the account owner in a

property power of attorney recognized as a statutory short form power of attorney for property.

(3) Such individual or entity that the account owner so designates in writing, in a manner to be established by the State Treasurer.

(4) Such other individual or entity designated by the State Treasurer pursuant to its rules.

"Disability certification" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Eligible individual" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Participation agreement" means an agreement to participate in the ABLE account plan between an account owner and the State, through its agencies and the State Treasurer.

"Qualified disability expenses" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Qualified withdrawal" or "qualified distribution" means a withdrawal from an ABLE account to pay the qualified disability expenses of the beneficiary of the account.

(b) The "Achieving a Better Life Experience" or "ABLE" account program is hereby created and shall be administered by the State Treasurer. The purpose of the ABLE plan is to encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life, and to provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, federal and State medical and disability insurance, the beneficiary's employment, and other sources. Under the plan, a person may make contributions to an ABLE account to meet the qualified disability expenses of the designated beneficiary of the account. The plan must be operated as an accounts-type plan that permits persons to save for qualified disability expenses incurred by or on behalf of an eligible individual.

The State Treasurer shall promote awareness of the availability and advantages of the ABLE account plan as a way to assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities. The cost of these promotional efforts shall not be funded with fees imposed on participants by the State Treasurer.

The State Treasurer shall not accept contributions for ABLE accounts under this Section until the Internal Revenue Service has issued its final regulations or interim guidance concerning ABLE accounts.

A separate account must be maintained for each beneficiary for whom contributions are made, and no more than one account shall be established per beneficiary. If an ABLE account is established for a designated beneficiary, no account subsequently established for such beneficiary shall be treated as an ABLE account. The preceding sentence shall not apply in the case of an ABLE account established for purposes of a rollover as permitted under Section 529A of the Internal Revenue Code.

An ABLE account may be established under this Section for a designated beneficiary who is a resident of Illinois, a resident of a contracting state, or a resident of any other state.

Prior to the establishment of an ABLE account, an account owner must provide documentation to the State Treasurer that the account beneficiary is an eligible individual.

Annual contributions to an ABLE account on behalf of a beneficiary are subject to the requirements of subsection (b) of Section 529A of the Internal Revenue Code. No person may make a contribution to an ABLE account if such a contribution would result in the aggregate account balance of an ABLE account exceeding the account balance limit authorized under Section 529A of the Internal Revenue Code. The Treasurer shall review the contribution limit at least annually.

The State Treasurer shall administer the plan, including accepting and processing applications, maintaining account records, making payments, and undertaking any other necessary tasks to administer the plan, including the appointment of an account administrator. The State Treasurer may contract with one or more third parties to carry out some or all of these administrative duties, including, but not limited to, providing investment management services, incentives, and marketing the plan.

In designing and establishing the plan's requirements and in negotiating or entering into contracts with third parties under this Section, the State Treasurer shall consult

with the Board. The State Treasurer shall establish fees to be imposed on participants to recover the costs of administration, recordkeeping, and investment management. The State Treasurer must use his or her best efforts to keep these fees as low as possible, consistent with efficient administration.

The Illinois ABLE Accounts Administrative Fund is created as a nonappropriated trust fund in the State treasury. The State Treasurer shall use moneys in the Administrative Fund to pay for administrative expenses he or she incurs in the performance of his or her duties under this Section. The State Treasurer shall use moneys in the Administrative Fund to cover administrative expenses incurred under this Section. The Administrative Fund may receive any grants or other moneys designated for administrative purposes from the State, or any unit of federal, state, or local government, or any other person, firm, partnership, or corporation. Any interest earnings that are attributable to moneys in the Administrative Fund must be deposited into the Administrative Fund. Any fees established by the State Treasurer to recover the costs of administration, recordkeeping, and investment management shall be deposited into the Administrative Fund.

Subject to appropriation, the State Treasurer may pay administrative costs associated with the creation and management of the plan until sufficient assets are available in the Administrative Fund for that purpose.

Applications for accounts, account owner data, account data, and data on beneficiaries of accounts are confidential and exempt from disclosure under the Freedom of Information Act.

(c) The State Treasurer may invest the moneys in ABLE accounts in the same manner and in the same types of investments provided for the investment of moneys by the Board. To enhance the safety and liquidity of ABLE accounts, to ensure the diversification of the investment portfolio of accounts, and in an effort to keep investment dollars in the State, the State Treasurer may make a percentage of each account available for investment in participating financial institutions doing business in the State, except that the accounts may be invested without limit in investment options from open-ended investment companies registered under Section 80a of the federal Investment Company Act of 1940. The State Treasurer may contract with one or more third parties for investment management, recordkeeping, or other services in connection with investing the accounts.

The account administrator shall annually prepare and adopt a written statement of investment policy that includes a risk management and oversight program. The risk management and oversight program shall be designed to ensure that an effective risk management system is in place to monitor the risk levels of the ABLE plan, to ensure that the risks taken are prudent and properly managed, to provide an integrated process for overall risk management, and to assess investment returns as well as risk to determine if the risks taken are adequately compensated compared to applicable performance benchmarks and standards.

The State Treasurer may enter into agreements with other states to either allow Illinois residents to participate in a plan operated by another state or to allow residents of other states to participate in the Illinois ABLE plan.

(d) The State Treasurer shall ensure that the plan meets the requirements for an ABLE account under Section 529A of the Internal Revenue Code. The State Treasurer may request a private letter ruling or rulings from the Internal Revenue Service and must take any necessary steps to ensure that the plan qualifies under relevant provisions of federal law. Notwithstanding the foregoing, any determination by the Secretary of the Treasury of the United States that an account was utilized to make non-qualified distributions shall not result in an ABLE account being disregarded as a resource.

A person may make contributions to an ABLE account on behalf of a beneficiary. Contributions to an account made by persons other than the account owner become the property of the account owner. Contributions to an account shall be considered as a transfer of assets for fair market value. A person does not acquire an interest in an ABLE account by making contributions to an account. A contribution to any account for a beneficiary must be rejected if the contribution would cause either the aggregate or annual account balance of the account to exceed the limits imposed by Section 529A of the Internal Revenue Code.

Any change in account owner must be done in a manner consistent with Section 529A of the Internal Revenue Code.

Notice of any proposed amendments to the rules and regulations shall be provided to all owners or their designated representatives prior to adoption. Amendments to rules and

regulations shall apply only to contributions made after the adoption of the amendment. Amendments to this Section automatically amend the participation agreement. Any amendments to the operating procedures and policies of the plan shall automatically amend the participation agreement after adoption by the State Treasurer.

All assets of the plan, including any contributions to accounts, are held in trust for the exclusive benefit of the account owner and shall be considered spendthrift accounts exempt from all of the owner's creditors. The plan shall provide separate accounting for each designated beneficiary sufficient to satisfy the requirements of paragraph (3) of subsection (b) of Section 529A of the Internal Revenue Code. Assets must be held in either a state trust fund outside the State treasury, to be known as the Illinois ABLE plan trust fund, or in accounts with a third-party provider selected pursuant to this Section. Amounts contributed to ABLE accounts shall not be commingled with State funds and the State shall have no claim to or against, or interest in, such funds.

Plan assets are not subject to claims by creditors of the State and are not subject to appropriation by the State. Payments from the Illinois ABLE account plan shall be made under this Section.

The assets of ABLE accounts and their income may not be used as security for a loan.

The assets of ABLE accounts and their income and operation shall be exempt from all taxation by the State of Illinois and any of its subdivisions to the extent exempt from federal income taxation. The accrued earnings on investments in an ABLE account once disbursed on behalf of a designated beneficiary shall be similarly exempt from all taxation by the State of Illinois and its subdivisions to the extent exempt from federal income taxation, so long as they are used for qualified expenses.

Notwithstanding any other provision of law that requires consideration of one or more financial circumstances of an individual, for the purpose of determining eligibility to receive, or the amount of, any assistance or benefit authorized by such provision to be provided to or for the benefit of such individual, any amount, including earnings thereon, in the ABLE account of such individual, any contributions to the ABLE account of the individual, and any distribution for qualified disability expenses shall be disregarded for such purpose with respect to any period during which such individual maintains, makes contributions to, or receives distributions from such ABLE account.

(e) The account owner or the designated representative of the account owner may request that a qualified distribution be made for the benefit of the account owner. Qualified distributions shall be made for qualified disability expenses allowed pursuant to Section 529A of the Internal Revenue Code. Qualified distributions must be withdrawn proportionally from contributions and earnings in an account owner's account on the date of distribution as provided in Section 529A of the Internal Revenue Code. Upon the death of a beneficiary, the amount remaining in the beneficiary's account must be distributed pursuant to subsection (f) of Section 529A of the Internal Revenue Code.

(f) The State Treasurer may adopt rules to carry out the purposes of this Section. The State Treasurer shall further have the power to issue peremptory rules necessary to ensure that ABLE accounts meet all of the requirements for a qualified state ABLE program under Section 529A of the Internal Revenue Code and any regulations issued by the Internal Revenue Service.

(Source: P.A. 99-145, eff. 1-1-16; 99-563, eff. 7-15-16.)

Heard About **ABLE** Accounts?

The concept is for individuals with disabilities to have a tax-free savings account similar to a 529 College Savings Plan (ABLE accounts will be "529A" accounts).

For information specifically on the State of Illinois ABLE Account program please visit:

<http://www.illinoistreasurer.gov/Individuals/ABLE>

However, Illinois residents can also use many other State's ABLE Account programs. The first State to have an ABLE Account, and many feel, arguably, the easiest to use, is Ohio's found at:

<http://www.stableaccount.com>

To compare the different State ABLE programs got to:

http://www.ablenrc.org/state_compare/

While an ABLE account may be a very useful additional "tool" in some circumstances, an ABLE account may not be as useful as first thought for many families of individuals with disabilities.

First, the ABLE account is limited in terms of the amount of money that can be deposited on an annual basis; the 2018 limit is \$15,000 per year, and there is a limit of one ABLE account per individual. However, in addition, beginning in 2018, due to the December 2017 Federal Tax Bill (the Tax Cuts and Jobs Act), until 12/31/25, an ABLE beneficiary who has income from employment may make an additional contribution of the lesser of the beneficiary's earned gross income from employment for the year, and an amount equal to the Federal Poverty Level for a one-person household (which is currently at \$12,060), if there is no contribution by or for the beneficiary, to an employer retirement saving plan. However, beware; the earned income will still be counted for purposes of eligibility. Additionally, the Tax Cuts and Jobs Act allows, beginning in 2018 until 12/31/25, a designated beneficiary of an ABLE account, to claim the saver's credit for contributions made by the beneficiary to his or her ABLE account, if not a full time student and if age 18 or older. Of note is another new provision regarding ABLE accounts under the December 2017 Federal Tax Bill. That is, in 2018 a traditional 529 college tuition account which has an ABLE beneficiary as the beneficiary, may be transferred to the 529A ABLE Account for that beneficiary, but the amount of the "rollover" is subject to the annual limitation for contributions, again \$15,000 for 2018.

Second, the total value of an ABLE account cannot exceed \$100,000 or the individual will have their SSI eligibility suspended until the account balance returns below that level. Further, the ABLE account is capped at the College Savings 529 Plan maximum in the state in which the ABLE account is open; State limits vary from approximately \$250,000 to \$450,000. Illinois' limit is \$400,000.

Third, ABLE accounts can be used solely to cover disability related expenses or face a penalty.

Fourth, an ABLE account requires strict, complex reporting and record keeping.

Fifth, the individual, unless there is a court appointed Guardian appointed, has full control and access to the Account. That is there is no "trustee" or "custodian".

Finally, be aware that the States that provided medical assistance and/or Medicaid waiver services during the life of the individual, such as Home Based or residential services, are allowed on the individual's death to claim a

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“payback” or reimbursement, for all such amounts (including medical and Medicaid waiver) which were provided to the individual after the establishment of the ABLE account.

There are several circumstances in which an ABLE account may be very useful. For example, in situations where an individual with disabilities wants to save excess work earnings or Social Security money so that it may be used in the future, as this money cannot be accumulated over \$2,000 in their own name (under SSI and “traditional” Medicaid rules) but they can place up to \$15,000 a year into an ABLE Account.

An ABLE account might also be useful where a relative has left an inheritance of less than \$15,000 directly to the child who is on “traditional” Medicaid and/or SSI and mistakenly did not leave it to a 3rd party Special Needs Trust.

Another possible use for an ABLE account might be to receive “adult” child support ordered by a court, in order not to impact SSI or Medicaid.

ABLE accounts could also be used to avoid the 1/3 reduction to SSI for family contributions to the individual for food and shelter. If the family contributes the funds for food and shelter to the Able Account, its use will not cause the 1/3 reduction to SSI as it would if such funds came from them directly or through a special needs trust.

Lastly, it might be the perfect vehicle for small litigation settlements.

However, due to the “payback” or reimbursement to the State(s) on death for Medicaid use, it is definitely not an appropriate vehicle for gifts or inheritances from others for the benefit of the individual with disabilities, unless there is the strong belief that all funds gifted will be spent for disability related expenses before the individual with disabilities dies. In that situation a Third Party Special Needs Trust is the only appropriate option and with a Third Party Special Needs Trust’s favorable income tax rules, that is, being taxed as a Qualified Disability Trust with a \$4,150 exemption in 2018, and with the beneficiary’s 2018 standard deduction of \$12,000, the Trust can shelter potentially (subject to the beneficiary’s earned income) more than \$16,000 in annual investment income.

In short, the ABLE account has some use for the individual’s own savings, but generally not for gifts or inheritances from others due to the pay-back on death of the individual.

Many believe that the most beneficial provision of an ABLE account is that it grows “income tax free”, at least for Federal Income Tax purposes. However, if you “do the math” you will see that, that fact is really of little benefit. If the individual is receiving SSI, the ABLE account cannot have more than \$100,000. The individual can use their 2018 standard deduction of \$12,000 to shelter their earned income and any income on ABLE account investments. Further, If you add the average individual’s (receiving SSI) annual earned income to the current possible return on \$100,000 in ABLE account investments, you will see that more than likely than not there wouldn’t be any income tax anyway on those funds, even if they were “taxable”.

It is important to remember the benefits as well as the shortcomings of ABLE accounts as you consider them as one of the savings tools for an individual with disabilities.

Before considering an ABLE account, when they become available, you should consult with an experienced special needs planning attorney. To find such an attorney we suggest visit <http://www.specialneedsalliance.org/find-an-attorney/illinois/> (the national not-for-profit association of experienced special needs planning attorneys, membership by invitation only).



Memorandum to clients regarding reporting of special needs trusts and ABLÉ Accounts to SSA and HGS

1. ***Report to SSA and HFS any Third Party Special Needs Trust, even if unfunded. Specifically state:***

"Exempt 3rd Party Special Needs Trust in accordance with 760 ILCS 5/15.1 (P.A. 89-205, eff. 1-1-96.), the Illinois Trusts and Trustees Act, and 405 ILCS 5/5-105, the Illinois Mental Health and Developmental Disabilities Code (P.A. 87-311; 88-380). SEE ATTACHED

2. ***Report to SSA and HFS any First Party Special Needs Trust. Specifically state:***

"Exempt 1st Party Special Needs Trust in accordance with 760 ILCS 5/15.1 (P.A. 89-205, eff. 1-1-96.), the Illinois Trusts and Trustees Act, and 405 ILCS 5/5-105, the Illinois Mental Health and Developmental Disabilities Code (P.A. 87-311; 88-380), and further, specifically pursuant to 42 U.S.C. Section 1396p(d)(4)(A), as amended by the Omnibus Reconciliation Act of 1993 (OBRA) and by Section 5007 of the 21st Century Cures Act entitled "Fairness in Medicaid Supplemental Needs Trusts, 305 ILCS 5/2.1a, and 89 Ill. Admin. Code, Ch. 1, Sec. 120.347." SEE ATTACHED

3. ***Report to SSA and HFS any ABLÉ Account. Specifically state:***

"Exempt ABLÉ Account in accordance with Public Law 113-295 ("The Tax Increase Prevention Act of 2014"), which established "The Stephen Beck, Jr., Achieving a Better Life Experience Act (ABLE Act)", enacted December 19, 2014.", and in accordance with Illinois Public Act 099-0145 (7-27-15), 15 ILCS 505/16.6". SEE ATTACHED

(760 ILCS 5/15.1) (from Ch. 17, par. 1685.1)

Sec. 15.1. Trust for a beneficiary with a disability. A discretionary trust 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 disability shall not be liable to pay or reimburse the State or any public agency for financial aid or services to the individual except to the extent the trust was created by the individual or trust property has been distributed directly to or is otherwise under the control of the individual, provided that such exception shall not apply to a trust created with the property of the individual with a disability or property within his or her control if the trust complies with Medicaid reimbursement requirements of federal law. Notwithstanding any other provisions to the contrary, a trust created with the property of the individual with a disability or property within his or her control shall be liable, after reimbursement of Medicaid expenditures, to the State for reimbursement of any other service charges outstanding at the death of the individual with a disability. Property, goods and services purchased or owned by a trust for and used or consumed by a beneficiary with a disability shall not be considered trust property distributed to or under the control of the beneficiary. A discretionary trust is one in which the trustee has discretionary power to determine distributions to be made under the trust.

(Source: P.A. 99-143, eff. 7-27-15.)

(405 ILCS 5/5-105) (from Ch. 91 1/2, par. 5-105)

Sec. 5-105. Each recipient of services provided directly or funded by the Department and the estate of that recipient is liable for the payment of sums representing charges for services to the recipient at a rate to be determined by the Department in accordance with this Act. **If a recipient is a beneficiary of a trust described in Section 15.1 of the Trusts and Trustees Act, the trust shall not be considered a part of the recipient's estate and shall not be subject to payment for services to the recipient under this Section except to the extent permitted under Section 15.1 of the Trusts and Trustees Act.** If the recipient is unable to pay or if the estate of the recipient is insufficient, the responsible relatives are severally liable for the payment of those sums or for the balance due in case less than the amount prescribed under this Act has been paid. If the recipient is under the age of 18, the recipient and responsible relative shall be liable for medical costs on a case-by-case basis for services for the diagnosis and treatment of conditions other than that child's disabling condition. The liability shall be the lesser of the cost of medical care or the amount of responsible relative liability established by the Department under Section 5-116. Any person 18 through 21 years of age who is receiving services under the Education for All Handicapped Children Act of 1975 (Public Law 94-142) or that person's responsible relative shall only be liable for medical costs on a case-by-case basis for services for the diagnosis and treatment of conditions other than the person's disabling condition. The liability shall be the lesser of the cost of medical care or the amount of responsible relative liability established by the Department under Section 5-116. In the case of any person who has received residential services from the Department, whether directly from the Department or through a public or private agency or entity funded by the Department, the liability shall be the same

regardless of the source of services. The maximum services charges for each recipient assessed against responsible relatives collectively may not exceed financial liability determined from income in accordance with Section 5-116. Where the recipient is placed in a nursing home or other facility outside the Department, the Department may pay the actual cost of services in that facility and may collect reimbursement for the entire amount paid from the recipient or an amount not to exceed those amounts determined under Section 5-116 from responsible relatives according to their proportionate ability to contribute to those charges. The liability of each responsible relative for payment of services charges ceases when payments on the basis of financial ability have been made for a total of 12 years for any recipient, and any portion of that 12 year period during which a responsible relative has been determined by the Department to be financially unable to pay any services charges must be included in fixing the total period of liability. No child is liable under this Act for services to a parent. No spouse is liable under this Act for the services to the other spouse who wilfully failed to contribute to the spouse's support for a period of 5 years immediately preceding his or her admission. Any spouse claiming exemption because of wilful failure to support during any such 5 year period must furnish the Department with clear and convincing evidence substantiating the claim. No parent is liable under this Act for the services charges incurred by a child after the child reaches the age of majority. Nothing in this Section shall preclude the Department from applying federal benefits that are specifically provided for the care and treatment of a person with a disability toward the cost of care provided by a State facility or private agency.

(Source: P.A. 99-143, eff. 7-27-15.)

(15 ILCS 505/16.6)

Sec. 16.6. ABLE account program.

(a) As used in this Section:

"ABLE account" or "account" means an account established for the purpose of financing certain qualified expenses of eligible individuals as specifically provided for in this Section and authorized by Section 529A of the Internal Revenue Code.

"ABLE account plan" or "plan" means the savings account plan provided for in this Section.

"Account administrator" means the person selected by the State Treasurer to administer the daily operations of the ABLE account plan and provide marketing, recordkeeping, investment management, and other services for the plan.

"Aggregate account balance" means the amount in an account on a particular date or the fair market value of an account on a particular date.

"Beneficiary" means the ABLE account owner.

"Board" means the Illinois State Board of Investment.

"Contracting state" means a state without a qualified ABLE program which has entered into a contract with Illinois to provide residents of the contracting state access to a qualified ABLE program.

"Designated representative" means a person who is authorized to act on behalf of an account owner. An account owner is authorized to act on his or her own behalf unless the account owner is a minor or the account owner has been adjudicated to have a disability so that a guardian has been appointed. A designated representative acts in a fiduciary capacity to the account owner. The State Treasurer shall recognize a person as a designated representative without appointment by a court in the following order of priority:

- (1) The account owner's plenary guardian of the estate, or the account owner's limited guardian of financial or contractual matters. Any guardian acting in this capacity shall not be required to seek court approval for any ABLE qualified distributions.

- (2) The agent named by the account owner in a property power of attorney recognized as a statutory short form power of attorney for

property.

(3) Such individual or entity that the account owner so designates in writing, in a manner to be established by the State Treasurer.

(4) Such other individual or entity designated by the State Treasurer pursuant to its rules.

"Disability certification" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Eligible individual" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Participation agreement" means an agreement to participate in the ABLE account plan between an account owner and the State, through its agencies and the State Treasurer.

"Qualified disability expenses" has the meaning given to that term under Section 529A of the Internal Revenue Code.

"Qualified withdrawal" or "qualified distribution" means a withdrawal from an ABLE account to pay the qualified disability expenses of the beneficiary of the account.

(b) The "Achieving a Better Life Experience" or "ABLE" account program is hereby created and shall be administered by the State Treasurer. The purpose of the ABLE plan is to encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life, and to provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, federal and State medical and disability insurance, the beneficiary's employment, and other sources. Under the plan, a person may make contributions to an ABLE account to meet the qualified disability expenses of the designated beneficiary of the account. The plan must be operated as an accounts-type plan that permits persons to save for qualified disability expenses incurred by or on behalf of an eligible individual.

The State Treasurer shall promote awareness of the availability and advantages of the ABLE account plan as a way to assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities. The cost of these promotional efforts shall not be funded with fees imposed on participants by the State Treasurer.

The State Treasurer shall not accept contributions for ABLE accounts under this Section until the Internal Revenue Service has issued its final regulations or interim guidance concerning ABLE accounts.

A separate account must be maintained for each beneficiary for whom contributions are made, and no more than one account shall be established per beneficiary. If an ABLE account is established for a designated beneficiary, no account subsequently established for such beneficiary shall be treated as an ABLE account. The preceding sentence shall not apply in the case of an ABLE account established for purposes of a rollover as permitted under Section 529A of the Internal Revenue Code.

An ABLE account may be established under this Section for a designated beneficiary who is a resident of Illinois, a resident of a contracting state, or a resident of any other state.

Prior to the establishment of an ABLE account, an account owner must provide documentation to the State Treasurer that the account beneficiary is an eligible individual.

Annual contributions to an ABLE account on behalf of a beneficiary are subject to the requirements of subsection (b) of Section 529A of the Internal Revenue Code. No person may make a contribution to an ABLE account if such a contribution would result in the aggregate account balance of an ABLE account exceeding the account balance limit authorized under Section 529A of the Internal Revenue Code. The Treasurer shall review the contribution limit at least annually.

The State Treasurer shall administer the plan, including accepting and processing applications, maintaining account records, making payments, and undertaking any other necessary tasks to administer the plan, including the appointment of an account administrator. The State Treasurer may contract with one or more third parties to carry out some or all of these administrative duties, including, but not limited to, providing investment management services, incentives, and marketing the plan.

In designing and establishing the plan's requirements and in negotiating or entering into contracts with third parties under this Section, the State Treasurer shall consult with the Board. The State Treasurer shall establish fees to be imposed on participants to

recover the costs of administration, recordkeeping, and investment management. The State Treasurer must use his or her best efforts to keep these fees as low as possible, consistent with efficient administration.

The Illinois ABLE Accounts Administrative Fund is created as a nonappropriated trust fund in the State treasury. The State Treasurer shall use moneys in the Administrative Fund to pay for administrative expenses he or she incurs in the performance of his or her duties under this Section. The State Treasurer shall use moneys in the Administrative Fund to cover administrative expenses incurred under this Section. The Administrative Fund may receive any grants or other moneys designated for administrative purposes from the State, or any unit of federal, state, or local government, or any other person, firm, partnership, or corporation. Any interest earnings that are attributable to moneys in the Administrative Fund must be deposited into the Administrative Fund. Any fees established by the State Treasurer to recover the costs of administration, recordkeeping, and investment management shall be deposited into the Administrative Fund.

Subject to appropriation, the State Treasurer may pay administrative costs associated with the creation and management of the plan until sufficient assets are available in the Administrative Fund for that purpose.

Applications for accounts, account owner data, account data, and data on beneficiaries of accounts are confidential and exempt from disclosure under the Freedom of Information Act.

(c) The State Treasurer may invest the moneys in ABLE accounts in the same manner and in the same types of investments provided for the investment of moneys by the Board. To enhance the safety and liquidity of ABLE accounts, to ensure the diversification of the investment portfolio of accounts, and in an effort to keep investment dollars in the State, the State Treasurer may make a percentage of each account available for investment in participating financial institutions doing business in the State, except that the accounts may be invested without limit in investment options from open-ended investment companies registered under Section 80a of the federal Investment Company Act of 1940. The State Treasurer may contract with one or more third parties for investment management, recordkeeping, or other services in connection with investing the accounts.

The account administrator shall annually prepare and adopt a written statement of investment policy that includes a risk management and oversight program. The risk management and oversight program shall be designed to ensure that an effective risk management system is in place to monitor the risk levels of the ABLE plan, to ensure that the risks taken are prudent and properly managed, to provide an integrated process for overall risk management, and to assess investment returns as well as risk to determine if the risks taken are adequately compensated compared to applicable performance benchmarks and standards.

The State Treasurer may enter into agreements with other states to either allow Illinois residents to participate in a plan operated by another state or to allow residents of other states to participate in the Illinois ABLE plan.

(d) The State Treasurer shall ensure that the plan meets the requirements for an ABLE account under Section 529A of the Internal Revenue Code. The State Treasurer may request a private letter ruling or rulings from the Internal Revenue Service and must take any necessary steps to ensure that the plan qualifies under relevant provisions of federal law. Notwithstanding the foregoing, any determination by the Secretary of the Treasury of the United States that an account was utilized to make non-qualified distributions shall not result in an ABLE account being disregarded as a resource.

A person may make contributions to an ABLE account on behalf of a beneficiary. Contributions to an account made by persons other than the account owner become the property of the account owner. Contributions to an account shall be considered as a transfer of assets for fair market value. A person does not acquire an interest in an ABLE account by making contributions to an account. A contribution to any account for a beneficiary must be rejected if the contribution would cause either the aggregate or annual account balance of the account to exceed the limits imposed by Section 529A of the Internal Revenue Code.

Any change in account owner must be done in a manner consistent with Section 529A of the Internal Revenue Code.

Notice of any proposed amendments to the rules and regulations shall be provided to all owners or their designated representatives prior to adoption. Amendments to rules and regulations shall apply only to contributions made after the adoption of the amendment.

Amendments to this Section automatically amend the participation agreement. Any amendments to the operating procedures and policies of the plan shall automatically amend the participation agreement after adoption by the State Treasurer.

All assets of the plan, including any contributions to accounts, are held in trust for the exclusive benefit of the account owner and shall be considered spendthrift accounts exempt from all of the owner's creditors. The plan shall provide separate accounting for each designated beneficiary sufficient to satisfy the requirements of paragraph (3) of subsection (b) of Section 529A of the Internal Revenue Code. Assets must be held in either a state trust fund outside the State treasury, to be known as the Illinois ABLE plan trust fund, or in accounts with a third-party provider selected pursuant to this Section. Amounts contributed to ABLE accounts shall not be commingled with State funds and the State shall have no claim to or against, or interest in, such funds.

Plan assets are not subject to claims by creditors of the State and are not subject to appropriation by the State. Payments from the Illinois ABLE account plan shall be made under this Section.

The assets of ABLE accounts and their income may not be used as security for a loan.

The assets of ABLE accounts and their income and operation shall be exempt from all taxation by the State of Illinois and any of its subdivisions to the extent exempt from federal income taxation. The accrued earnings on investments in an ABLE account once disbursed on behalf of a designated beneficiary shall be similarly exempt from all taxation by the State of Illinois and its subdivisions to the extent exempt from federal income taxation, so long as they are used for qualified expenses.

Notwithstanding any other provision of law that requires consideration of one or more financial circumstances of an individual, for the purpose of determining eligibility to receive, or the amount of, any assistance or benefit authorized by such provision to be provided to or for the benefit of such individual, any amount, including earnings thereon, in the ABLE account of such individual, any contributions to the ABLE account of the individual, and any distribution for qualified disability expenses shall be disregarded for such purpose with respect to any period during which such individual maintains, makes contributions to, or receives distributions from such ABLE account.

(e) The account owner or the designated representative of the account owner may request that a qualified distribution be made for the benefit of the account owner. Qualified distributions shall be made for qualified disability expenses allowed pursuant to Section 529A of the Internal Revenue Code. Qualified distributions must be withdrawn proportionally from contributions and earnings in an account owner's account on the date of distribution as provided in Section 529A of the Internal Revenue Code. Upon the death of a beneficiary, the amount remaining in the beneficiary's account must be distributed pursuant to subsection (f) of Section 529A of the Internal Revenue Code.

(f) The State Treasurer may adopt rules to carry out the purposes of this Section. The State Treasurer shall further have the power to issue peremptory rules necessary to ensure that ABLE accounts meet all of the requirements for a qualified state ABLE program under Section 529A of the Internal Revenue Code and any regulations issued by the Internal Revenue Service.

(Source: P.A. 99-145, eff. 1-1-16; 99-563, eff. 7-15-16.)

DELEGATION OF RIGHTS TO MAKE EDUCATIONAL DECISION

On this _____ day of _____, 20____, I, _____, execute this Delegation of Rights, in express accordance with and pursuant to **Public Act 095-0372, which amended the Illinois School Code by adding Section 14-6.10 (105 ILCS 5/14-6.10), "TRANSFER OF PARENTAL RIGHTS AT THE AGE OF MAJORITY", effective 8/23/2007.**

I, _____, am 18 years of age or older and a student who has the right to make educational decisions for myself under State and federal law. I have not been adjudged incompetent and, as of the date of the execution of this document, I hereby delegate my right to give consent and make decisions concerning my education to _____, My Designated Representative, who will be considered my "parent" for purposes of the Individuals with Disabilities Education Improvement Act of 2004 and Article 14 of the School Code and will exercise all of the rights and responsibilities concerning my education that are conferred on a parent under those laws. I understand and give my consent for My Designated Representative, to make all decisions relating to my education on my behalf. I understand that I have the right to be present at meetings held to develop my individualized education program and that I have the right to raise any issues or concerns I may have and that the school district must consider them. This delegation will be in effect for one year from the date of execution of this document, and may be renewed by my written or other formal authorization. I also understand that I have the right to terminate this Delegation of Rights at any time and assume the right to make my own decisions regarding my education. I understand that I must notify the school district immediately if I revoke this Delegation of Rights prior to its expiration.

Student

Accepted by:

Designated Representative



Special needs require special lawyers.

This Document Prepared by:

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Our law practice is limited to "special needs legal and future planning" for our fellow Illinois families of individuals with special needs, including, but not limited to, intellectual disabilities, developmental disabilities, and/or mental illness.

(Attorney memberships include the Special Needs Alliance and the Academy of Special Needs Planners)

(625 ILCS 5/6-103) DRIVER'S LICENSE Individual with Physical or Mental Disability

Sec. 6-103. The Secretary of State shall not issue, renew, or allow the retention of any driver's license nor issue any permit under this Code:

5. To any person, as a driver, who has previously been adjudged to be afflicted with, or suffering from, any mental or physical disability or disease and who has not at the time of application been restored to competency by the methods provided by law;

8. To any person when the Secretary of State has good cause to believe that the person by reason of physical or mental disability would not be able to safely operate a motor vehicle upon the highways, unless the person shall furnish to the Secretary of State a verified written statement, acceptable to the Secretary of State, from a competent medical specialist to the effect that the operation of a motor vehicle by the person would not be inimical to the public safety;

...

(Source: P.A. 92-343, eff. 1-1-02.)

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ANNOUNCEMENT

NEW ILLINOIS LAW – REQUIRED TRAINING FOR GUARDIANS

Be advised that a new law was recently passed in Illinois regarding required training for Guardians, even for parents, of disabled adults (Public Act 100-483), effective September 8, 2018, except for some reason, not applicable to Cook County. The new law requires guardians of the person appointed in counties of less than three million (all counties except Cook) to complete a training program within one year from the date of appointment. Public guardians, licensed attorneys, and corporate fiduciaries are exempted from this requirement. **A court may exempt, for good cause shown, any other person so appointed.**

New Section 33.5 of the Guardianship and Advocacy Act provides:

“The State Guardian shall provide a training program that outlines the duties and responsibilities of guardians appointed under Article XIa of the Probate Act of 1975. The training program shall be offered to courts at no cost, and shall outline the responsibilities of a guardian and the rights of a person with a disability in a guardianship proceeding under Article XIa of the Probate Act of 1975. In developing the training program content, the State Guardian shall consult with the courts, State and national guardianship organizations, public guardians, advocacy organizations, and persons and family members with direct experience with adult guardianship. In the preparation and dissemination of training materials, the State Guardian shall give due consideration to making the training materials accessible to persons with disabilities.”

755 ILCS 5/11a of the Probate Act (Adult Guardianship) was amended by adding:

“The order of appointment of a guardian of the person in any county with a population of less than 3 million shall include the requirement that the guardian of the person complete the training program as provided in Section 33.5 of the Guardianship and Advocacy Act that outlines the responsibilities of the guardian of the person and the rights of the person under guardianship and file with the court a certificate of completion one year from the date of issuance of the letters of guardianship, except that: (1) the chief judge of any circuit may order implementation of another training program by a suitable provider containing substantially similar content; (2) employees of the Office of the State Guardian, public guardians, attorneys currently authorized to practice law, corporate fiduciaries, and persons certified by the Center for Guardianship Certification are exempt from this training requirement; and (3) the court may, for good cause shown, exempt from this requirement an individual not otherwise listed in item (2). For the purposes of this subsection (e), good cause may be proven by affidavit.”

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(Attorney memberships include the Special Needs Alliance and the Academy of Special Needs Planners)

Some helpful information in regards to Powers of Attorney and Guardianship for our fellow families of children and adults with special needs...

Introduction

When a child with special needs turns 18, they become an adult in the eyes of the law. At that moment, all rights that a parent ordinarily has to make decisions for their children end. While this is part of the normal course of affairs for most children as they often leave their home to attend college at this age, and thus it makes sense that the law presumes them capable of handling their own affairs, for those with special needs the loss of these parental rights may be a frightening possibility. To forestall the imminent loss of their decision-making rights with regard to their special needs child, parents have a number of options.

I. Doing Nothing (Health Care Surrogate Act)

First, they can choose to do nothing. Under the Illinois Health Care Surrogate Act, if an individual's attending physician or hospital determines that the patient is unable to make his or her own medical decisions, and there is no applicable health care power of attorney, no court appointed guardian, no spouse, and the

child does not have their own adult son or daughter, then either parent can make medical decisions, including the Living Will decision for their child.

II. POWERS OF ATTORNEY

The Illinois Health Care Surrogate Act, however, only applies to medical decisions, thus when a special needs child turns 18, if the parents fail to take any other action, they will lose all rights to make decisions regarding, or even to talk to, the school, State and Federal agencies regarding Medicaid and SSI, employers, or any other organization providing residential services or day programs, etc. In order to prevent this from happening, the first, and least restrictive step that a parent of a special needs child can take, is to have their child sign several different powers of attorney to ensure that the parents have the right to talk to and make decisions regarding all of the abovementioned subjects.

These powers of attorney should include the Special Education Power of Attorney which has been in existence under Illinois law since August 2007, the Power of Attorney for the Social Security Administration, which handles SSI (which requires its own form), the Power of Attorney for the Illinois Department of Human Services which handles Medicaid (which requires its own form), as well as the Illinois Statutory Power of Attorney for Property (financial), a form just revised in July 2011, to allow the parents to handle their child with special needs' financial affairs. This financial power of attorney needs to include several additional provisions to the standard statutory form in order to permit the parent to handle matters pertaining to the IRS, speaking to organizations providing residential services and day programs, etc. Parents should also have their child with special needs sign an Illinois Statutory Power of Attorney for Health Care, also recently revised as of July 2011, to ensure they can make healthcare decisions for their child without recourse to the Health Care Surrogate Act which is dependent on the doctor or hospital determining that

their patient is not competent to make his or her own medical decisions. In addition there is a Mental Health Treatment form, which, if signed, can permit involuntary admission into a psychiatric hospital (a power even guardianship does not include in Illinois).

III. GUARDIANSHIP

While Powers of Attorney may be all that is appropriate for many individuals with special needs, they do not terminate the rights of the individual with special needs. Thus, if the individual signs a contract, it is binding. If the school convinces him or her that they do not want their parents to come to the next IEP, then the parents may never find out about it. Powers of attorney only work if the child lets them work and no one tries to take advantage of the situation. If more protection is needed, the next step is to go into court and obtain a Guardianship over the individual with special needs. Guardianships come in two main forms: a Limited Guardianship and a Plenary (full) Guardianship.

a. LIMITED GUARDIANSHIP

A Limited Guardianship basically says that the individual needs help in making decisions in a few areas listed in the court order. For instance, the Limited Guardianship might be for just medical and financial decisions. Once the list on the court order becomes longer than a few items, however, the court will likely require a Plenary (full) Guardianship instead. Families will often pursue this version of a Guardianship where the individual with special needs wants to maintain the ability to drive, as under a Plenary Guardianship, it is against Illinois State law to maintain a driver's license. This type of Guardianship is also often used where the individual is very "high functioning" and the court process of getting a Plenary Guardianship might be deemed too difficult emotionally for the child with special

needs. Finally, this type of Guardianship may be obtained to avoid the risk of liability that accompanies a Plenary (full) Guardianship, as discussed below.

b. PLENARY (FULL) GUARDIANSHIP

Plenary Guardianship is the most protective action that can be taken when a child with special needs becomes an adult. Under Plenary Guardianship the child is, for all intents and purposes, 17 again. The parent is thus able to act, this time in the role of “guardian of an adult disabled person,” as they were able to before the child became an adult. Under this form of Guardianship, when a serious incident occurs while the individual with special needs is living in a CILA, at school, at a work shop or DT program, the staff must contact the guardians as they would a parent of a minor child.

While under powers of attorney, the child with special needs is free to make his or her own decisions, with a Plenary Guardianship, any contract or decision made by the individual is void, not merely voidable. Furthermore, the child with special needs may not obtain a driver’s license and if he or she currently possesses one at the time of the Plenary Guardianship, it becomes void. The individual with special needs may still exercise his or her right to vote, however.

c. WHY DO SOME PARENTS/SIBLINGS DECLINE TO BECOME PLENARY (FULL) GUARDIANS?

The most common reason that parents decline to become legal guardian is fear of liability. Plenary Guardians may be liable in the event the child injures someone or damages property while under their supervision and they are deemed negligent in supervising the individual with special needs. However, the guardian’s authority, and

thus liability, is delegated to the school district if the child is in school, to the organization running the CILA if the child is living in a group home, and to the organization running the day program while the child is there. If Parents or siblings are nonetheless hesitant to seek Plenary Guardianship due the risk of liability, a Limited Guardianship, discussed above, may be an appropriate alternative.

d. THE PROCESS OF BECOMING LEGAL GUARDIAN FOR AN ADULT WITH SPECIAL NEEDS

The process of obtaining a Guardianship has all the formalities of a court case. A Guardianship is a serious matter, it declares that the person is legally incompetent to handle their affairs, it strips them of all of the ordinary rights all other adults have. Because of the gravity of the action, the procedure includes several safeguards.

1. First, a lawsuit is filed by those seeking to become legal guardian. A report by a doctor (must be an Illinois licensed M.D., not a psychologist) who has examined the child within 90 days of the filing of the lawsuit must be submitted.
2. A sheriff summons must be issued (the individual with special needs must be served physically with the summons).
3. If the individual with special needs objects to having a guardian appointed, the judge will appoint a Guardian Ad Litem to represent the interests of the individual with special needs to determine whether he or she needs a guardian and whether those seeking to become guardian are the best suited for that role. The cost of the Guardian Ad Litem will be borne by those seeking the Guardianship.
4. Parents can be “co-guardians”, as can siblings, but both signatures are required when acting as Guardians.

5. If an individual with special needs has money in their name, a guardianship of the estate, in addition to the guardianship of the person, must be opened and the court will supervise the management and disbursement of all the individual's funds. Special Needs Trusts, however, are not considered assets of the person, the Trust beneficiary.
6. Once Guardianship is established, annual reports (a simple two page form) must be filled out and mailed into the court each year (some counties, every two years, some every three years, some never, but in the collar counties, every year). The only time that Guardians must commonly go back in to court is for residential placement. When the Guardians determine that it is time for the child to be placed in a residential setting such as a CILA, they must go back into court to get this approved.
7. The Guardian can move out of State without going to court, but if the individual with special needs moves out of state, then the Guardianship must either be transferred or closed and reopened in the new state. If the Guardian, the individual with special needs, or both, move out of the county the Guardianship is in, the court may choose to move it to the new county. However, Illinois state law does not require this so, as long as it is disclosed in the annual reports, no further action is required unless the court says otherwise.

IV. WHEN TO SEEK GUARDIANSHIP

There is no rule about when to seek guardianship; in some cases it makes sense to do it at 18, in others to wait until the individual moves into a CILA, in still others powers of attorney will work just fine. It depends on the needs and circumstances of the individual with special needs.

V. NOMINATION OF SUCCESSOR GUARDIANS IN A WILL

In addition to nominating Guardians for minor children, parents of children with special needs must also nominate Guardians for an “Adult Disabled Person”. This nomination is not an appointment and must be approved by a court, but it carries tremendous weight when a court is determining whom to appoint as guardian for the individual with special needs. When considering who to nominate for such an important position, consider who would be the best person in the next few years as well as “back-up” people who you would want to step in if those people are unable or unwilling to step-up. As Guardian, they will not be required to have the individual with special needs move in with them, but they will be responsible for where the individual lives as well as for making all kinds of decisions regarding their living arrangements, day programs, etc.

VI. SHORT-TERM/STAND-BY GUARDIAN DECLARATIONS

When the Guardians go on vacation, they may fill out a Short-Term Guardian Declaration which temporarily delegates their guardianship authority to someone else. If a Guardian becomes incapacitated he or she may designate a Stand-by Guardian to serve during his or her incapacity. The designation of a Stand-by Guardian is traditionally done at the same time and using the same individuals as are nominated in a will. A sample Short Term Guardian Declaration is attached.

So you have Questions?

➔ **How is Rubin Law
“different” than
Other law firms?**

➔ **What does it cost?**

➔ **What is “included”
in that cost?**

➔ **What is the 1st step?**

A message from Brian Rubin:

1. **Our law firm's practice is limited to serving our fellow families of children with special needs...** not concentrated, but limited. That is all we do. I have been in practice since 1976. Since 1982, when my own son, Mitch, who has Autism, was one year old, my professional practice, as well as my personal time, has been devoted to planning for the future of my fellow families of children and adults with special needs. Our firm's mission is to provide Special Needs Future Planning, with compassion and understanding, for our fellow Illinois families of children and adults with special needs. My youngest son, Benjamin (Benji), Mitch's younger brother is an attorney and joined the family firm in 2010. Our firm also includes attorneys Judie Smith and Melanie Hoffman, as well as paralegal Jill Jill Yonover, and legal assistants of my daughter, Nicole Rosenthal, my wife, Linda Rubin, Karen Muschkat, and Carmen Cuzmanko, herself a mother of a son with autism. My son Mitchell, who has autism also works in our office part-time.
2. **The first step in the process is that the family will have an Office Consultation.** This meeting normally lasts approximately two (2) hours. During this meeting, we will:
 - a. Review your personal family situation;
 - b. Review your current or existing Wills and Trusts, including any Special Needs Trusts, Powers of Attorney, and Living Wills, if any;
 - c. Explain the who, what, where, when, why and how of Government Benefits, such as SSI, Medicaid, SSDI and Medicare for adults with special needs;
 - d. Discuss Special Education Transition Planning "tips" and "advice" if the child is still in school;
 - e. Discuss State programs and services available, regardless of parents' assets or income, prior to child turning 18;
 - f. Discuss State programs and services available after the child is 18, even while the child is still in school and/or still at home, regardless of parents assets and income;
 - g. Provide practical advice and guidance on accessing post school, post 22, State programs and services, such as:
 - i. Supported Employment
 - ii. Sheltered Employment (Regular Work)
 - iii. Developmental Training (DT)
 - iv. In Home Services
 - v. Residential Options
 - h. Discuss and provide guidance on selecting guardians for when parents have passed on, are elderly, or have lost capacity, for your minor children and in particular, your child with special needs;

- i. Discuss selecting Trustees, that is, the individuals who will watch the money for your children, in particular, your child with special needs, when you are no longer able to do so;
 - j. Discuss how the Special Needs Trust will operate, will work, in ***"plain English"***;
 - k. Provide guidance on educating the extended family and friends, such as siblings, grandparents, Aunts and Uncles on the need to modify their estate plan documents;
 - l. Provide guidance on opportunities if a relative needs to go into a Nursing Home... how the Special Needs Trust for their child could be used to secure Medicaid for that relative;
 - m. Provide guidance on special required documentation if the parents are, or in the future are, divorced, due to there being a child with special needs;
 - n. Provide guidance on dividing assets remaining when the parents pass on between the child with special needs and the other child or children;
 - o. Provide guidance on leaving instructions for future Guardians and Trustees of their child with special needs;
 - p. Discuss the appropriate State documents for when parents are out of town and their child or children are in the care of others;
 - q. Discuss the appropriate State documents in the event that the parents or legal Guardians are still living but not physically or mentally competent to care for minor children, in particular, a child with special needs;
 - r. Discuss alternatives to "dividing the pot" among the children when there is a child with special needs;
 - s. Discuss Guardianship for children 18 or older, and the possible alternatives (see more on this topic below);
 - t. Discuss Federal and Illinois Estate Tax Planning, when appropriate;
 - u. Discuss the advantages of Probate Avoidance;
 - v. Answer all of your questions.
3. ***The fee for the Initial Consultation described above, is \$500.*** At the conclusion of the consultation, we will make recommendations as to the estate plan, or revised estate plan, necessary and appropriate for your unique situation. We have a "fixed" or "flat", all-inclusive, schedule of fees, for such services. Regretfully, it is impossible for us to tell you what documents you will need, or which fees from the fee schedule are applicable until I meet with you, review your individual family situation, learn more about your child with special needs, as well as those of your other children, and understand your desires and your requests.

4. The “all inclusive” fee that will be provided to you at that time, includes:

- a. The Initial Consultation;**
- b. Our drafting for your review of all appropriate documents, including, as may be appropriate for your estate and family situation:
 - i. Wills, including provisions for non-special needs children;**
 - ii. Third Party Special Needs Trusts for inheritances and gifts;**
 - iii. First Party “OBRA 93 Pay Back” Special Needs Trust for medical malpractice, personal injury or other law suit settlements, as well as miss-directed inheritances and other assets of the child;**
 - iv. Revocable Living Trusts, including transfer of residence;**
 - v. Irrevocable Life Insurance Trusts;**
 - vi. Charitable Trusts;**
 - vii. Form letters, letters of instructions and certifications for all Trusts;**
 - viii. Declarations of Trust Ownership;**
 - ix. Sworn Declarations of Estate Planning Intent, for married couples “in case of” subsequent divorce;**
 - x. Durable Statutory Powers of Attorney for Property for financial matters;**
 - xi. Durable Statutory Powers of Attorney for Health Care;**
 - xii. Illinois Statutory Living Wills;**
 - xiii. Illinois Statutory Health Surrogate Act Declarations for child with special needs;**
 - xiv. Illinois Statutory Short Term Guardian Declarations;**
 - xv. Among other documents.****
- c. A binder of all proposed documents for your review;**
- d. All necessary changes and modifications to those draft documents, that you may request;**
- e. Phone consultations in regards to your questions regarding the draft documents;**
- f. A second Office Consultation, which normally will last approximately ninety (90) minutes to two (2) hours, to review and explain the documents, in as little or as much detail as you desire, followed by the signing of all of the documents in the presence of our provided witnesses and Notary Public;**
- g. A bound copy of all of the signed, witnessed and notarized documents;**
- h. A permanent envelope containing all of the original documents;**
- i. Instruction Letters;**
- j. Form letters and Trust Certifications;**

- k. After the second Office Consultation at which the documents are signed, we continue to provide ongoing services to our clients for no additional charges, unlike most other law firms. That is, we provide the following services, not usually provided by attorneys (except for additional hourly fees), so long as we prepared your estate plan, such as:
- i. Answering telephone questions of clients on government benefits;
 - ii. Answering telephone questions on transition planning;
 - iii. Answering telephone questions on post 21 programs and agencies;
 - iv. Consult with client's personal injury, corporate, or divorce lawyers;
 - v. Consult with clients regarding beneficiary changes, title changes and funding (opening accounts) in the name of the trust, if desired;
 - vi. Consult with extended family, and the extended family's attorneys as to their need to, "just in case", address the fact in their estate plan, that there is a potential heir who has special needs;
 - vii. Defend the Special Needs Trust(s), if required, before government agencies;
 - viii. Advise clients of changes in laws, regulations, or administrative rules that might affect the Special Needs Planning;
 - ix. Provide introductions for clients to individuals at agencies providing services;
 - x. Among other services.

More on Guardianship...

Having individuals appointed Guardians for someone over 18 is a court proceeding. We can arrange that service in the counties of Cook, Lake, DuPage, Kane and McHenry. The "fixed" or "flat" all-inclusive fee is also reflected on a fee schedule. The fee is dependent upon which county the individual with special needs has his or her permanent residence, and certain other circumstances, such as the marital situation of the parents, cooperation of the person/child, cognitive level of the individual/child, etc. We also prepare Short term and Stand By Guardian Declarations as part of our representation, so that the Guardian is able to delegate to someone else their Guardian responsibility if they are out of town, or if they become unable to serve due to disability, such as a stroke, etc.

More Questions ?

If you have additional questions about our firm and its approach, please call us at 847.279.7999, or outside of the Chicago Metro Area, Toll Free at 866.To.Rubin. Please also visit our web site at www.rubinlawcorp.com.

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".

Special Needs Future Planning includes, in addition to "normal" or "traditional" estate planning, Discretionary Supplemental or Special Needs Trusts, OBRA 93 or Medicaid "Pay-Back" Trusts, Adult Guardianship & alternatives, Health Surrogate Act Declarations, forms and language for the extended family to "piggy-back" on the Special Needs Trust, coordinating beneficiary designations for life insurance, IRAs, 401ks, pensions & profit sharing, planning for "post 18" child support if parents are divorced, Short-Term & Stand-By Guardian Declarations, special provisions and modifications to the parents' Wills, Living Trusts, Powers of Attorneys, as well as help with Medicaid, SSI, residential, day programs, employment issues & many, many related other matters.

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RUBIN LAW... THE VALUE ADDED **HOW WE ARE DIFFERENT**

Our law firm's commitment, our mission, is, with compassion and understanding, to always be there for our clients*, our fellow families of individuals with intellectual disabilities, developmental disabilities, and/or mental illness.

Unlike most law firms and attorneys, our fees are "fixed" fees, not hourly, for all services rendered. Clients are never "on the clock", never on a meter. Our policy is, and has always been, that we do not charge clients for phone calls, email communication, written correspondence, or future office conferences that the clients have with attorneys and/or staff of Rubin Law, or that the attorneys and/or staff of Rubin Law have with third parties at the request of the client(s), specifically including, but not limited to, any matter related to the clients' estate plan documents, contacts with State of Illinois Agencies, the Social Security Administration, and/or the Internal Revenue Service, regarding any drafted special needs trusts, questions related to government benefits, questions related to navigating the "maze" of the State of Illinois' children and adult programs, as well as questions "broadly" related to special needs legal and future planning. There is no annual maintenance fee. We want clients to call. There is no such thing as a "silly" question.

The only time there could be additional fees is if the clients request additional services after the clients sign their estate plan documents, such as for:

1. Changes to their estate plan documents, or additional estate plan documents
2. Adult Guardianship Probate Court Proceedings
3. Estate or Trust administration upon the death of the client(s)

As to the three items listed above, we would first have a phone consult or an in office meeting (this is at no charge to the client(s), as outlined above) to discuss the possible changes or additional documents, any possible Guardianship proceeding, and/or Estate/Trust Administration, at which time client(s) are informed of the fixed fee for such services. At that time the clients have the choice to either proceed with the discussed services, for the fixed fee quoted, or not to proceed. A new Attorney Fee Agreement would be required for such additional services.

Please note that if the clients establish new or additional estate plan documents, or amend and/or change any existing estate plan documents prepared by Rubin Law, with another attorney or law firm, or engage such other attorney or law firm for guardianship representation, additional fees may apply for any and all future services by Rubin Law.

*client(s) are individual(s) who have executed a Rubin Law "ATTORNEY FEE AGREEMENT - ESTATE PLANNING"

MEMBER



Special needs require special attorneys.



THE AMERICAN COLLEGE OF
TRUST AND ESTATE COUNSEL



For Ethical Standards and Legal Ability™



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About...

(First Name)

(Middle Name or Initial)

(Last Name)

Prepared on: _____

(Date Last Revised)

Prepared by: _____

Relationship: _____

Day Telephone: _____

Evening Telephone: _____

Emergency Cell Telephone: _____

Email: _____

Home Address: _____

To our fellow families of children with special needs and to our other children, the siblings of that child:

This document is being shared as a suggested "form" for what is commonly referred to as a "Letter of Intent", or guidance to future care providers, Guardians, Trustees, etc.

We suggest that you use the form as a guide, and prepare your own document on your computer. That way, annually, or even more often, you can revise, or modify, the document. Save the document, possibly as a "PDF", and forward it to your child's team, or "future" team.

Not all of the sections in this form may be relevant to your child or sibling. That is what the delete button on your key board is for.

If you have suggestions on how we may be able to improve upon this form, please be so kind to share them with us.

Finally, in addition to this document, please prepare a one or two page list of "bullet points", or what someone needs to know, immediately, to care for your child... say for the 24 to 48 hours, after they become responsible, possibly when you pass away. Next to some of the bullet points you should note, or reference, that there is more information on that "point", or to see page "X, of the full document. Remember that staff at an agency that may know your child very well, do get sick, do go on vacation, do retire, do quit... so these bullet points for "fill-in" or new staff is very, very important, as it is for your other family members and friends who will be responsible or who will be "stepping into our shoes".

Brian Rubin

Chapter One: Who?

Date of Birth: _____

Place of Birth: _____ (city) _____ (county)
 _____ (state) _____ (country)

Copy of birth certificate is attached.	Yes	No
A recent photograph is attached.	Yes	No
Registered to vote.	Yes	No
A copy of my voter registration card is attached.	Yes	No

My blood type is: _____

The best way for me to understand what you say is: _____

The best way for *you* to understand what I say is: _____

Tools that help me communicate include: _____

The way I communicate is:

My primary means of mobility is: (i.e.: wheelchair, cane, walking ... etc.)

Wear glasses: YES NO

Wear contacts:	YES	NO
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Wear a hearing device: YES NO

Other special equipment I use:

I remember and/or learn best by:

Chapter Two: What Describes Me?

I am most often (i.e. happy, talkative, friendly, playful, shy, quiet, withdrawn, assertive, passive, easily influenced, etc.):

I might become upset if the following happens:

When I become upset, this is what I look like:

Some of the things that help me to calm down (or comfort me) are:

Some things others can do to help me when I am upset (help me to calm down):

Things that make me happy are:

Things that make me sad are:

Things that scare me are:

Ways to help me prepare for scheduled events:

Things that help me to deal with a loss (loss of family member(s), loss of a staff - whether if different job or death, loss of a friend) are:

Some things that help me prepare for and deal with change:

Things that motivate me (help get me going):

After I've accomplished a task, or done something well:

To let me know I've done something well, I like it when:

If I should make a mistake or fail at something, I like it if:

I own the following:

I would be "lost" without these possessions:

Habits and/or routines I have are:

Chapter Three: My Interests

I like to do the following, on my own:

With others, I like to do the following:

When I'm at home, I like to:

When out in the community, I like to:

When I'm at home, I don't like to:

When out in the community, I don't like to:

When out in the community I need help with:

Some of my favorite recreation and/or leisure activities are:

Some recreation and/or leisure activities I don't like are:

Recreation and/or leisure activities I need assistance with:

My favorite places to visit are:

The people I like to go places with are:

Name: _____
Relationship: _____
Phone #/Email: _____

Name: _____
Relationship: _____
Phone #/Email: _____

Name: _____
Relationship: _____
Phone #/Email: _____

Some of my favorite vacations were:

My dream vacation is:

Activities that are good for exercise, that I like include:

I belong to a library: YES NO

If yes, the name and location of the library are:

I belong to the following clubs:

Hobbies I enjoy are:

Chapter Four: Household Tasks

I am able to do the following household tasks:

I enjoy doing the following household tasks:

I will need some assistance with the following household tasks:

I prefer not to do the following household tasks:

When it comes to food preparation and clean up I can:

I need assistance with the following:

I would like to learn how to:

Chapter Five: Food Interests

I like to eat the following foods:

I don't like the following foods:

I like eat at the following restaurants:

I am on a "special" diet. Yes No

If "yes", that diet consists of:

Additional information regarding my diet:

Chapter Six: My Family Tree

The members of my family:

[illegible]

(If possible, attach birth, death, and marriage certificates)

My family celebrates the following events (birthdays, holidays, anniversaries):

There is a history of certain medical conditions in my family. Specifically:

I would like to increase my participation in the following ethnic, cultural, and/or religious celebrations:

I would like to continue participating in the following ethnic, cultural, and/or religious celebrations:

My close friends include:

Name	Address	Phone/Email	Know From	Comments
<hr/>	<hr/>	<hr/>	<hr/>	<hr/>
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<hr/>	<hr/>	<hr/>	<hr/>	<hr/>

Other important people in my life are:

Name	Address	Phone/Email	Know From	Comments

Chapter Seven: Home

I currently live at:

My phone number is: _____

I live with:

I share a room. YES NO

If yes, I share my room with: _____

I have the following pets:

Comments about my current living situation:

People I like to visit with:

In the future, I would like to live:

In the future, I would like to live with:

In the future, I would NOT like to live with (reason):

Feature my home should have, to meet my needs include:

I need to live near (include reason):

Chapter EIGHT: Educational Background

School Name (current & past)	Address	Dates Attended	Contact Info. Email	Program Description/ Comments
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

I plan to stay in Special Education up to the age of 22:	Yes	No
An IEP it is attached (if applicable).	Yes	No
A transition plan it is attached (if applicable).	Yes	No
My last Psychological Evaluation is attached (if applicable).	Yes	No
My last IQ or comparable test is attached (if applicable).	Yes	No

I learn best when/by:

My future educational needs include:

People who know me the best at school:

Name	Phone Number
_____	_____
_____	_____
_____	_____

Additional information regarding my educational experience:

Chapter Nine: A Typical Day

I have a job.	YES	NO
If yes: Competitive Employment:	YES	NO
Supported Employment:	YES	NO
Regular Work (Sheltered/Workshop):	YES	NO
I go to a day (D.T.) program.	YES	NO
I am a volunteer:	YES	NO

Information on those responded "YES" to above:

Name	Address	Phone Number/Email

In the future, I would like the following type of employment, volunteer work and/or day program:

Past experiences with employment, volunteer work and/or day programming that you should be aware of are:

Chapter Ten: Religion/Spiritual

I worship/pray at:

Contact Information for the above (Name/Address/Phone/Email):

I participate by:

Chapter Eleven: Health Care History, Needs & Current Services

My diagnosis is:

Other medical conditions include:

Primary doctor(s) information:

Name (Doctor)	Address	Phone/Email	Years (seen by this doctor)	Comments
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

My past experience with my doctor(s) that I wish to share can be described by:

Eye doctor information:

Name (Doctor)	Address	Phone/Email	Years (seen by this doctor)	Comments
_____	_____	_____	_____	_____

My past experience with my eye doctor can be described by:

Dentist information:

Name (Doctor)	Address	Phone/Email	Years (seen by this doctor)	Comments
_____	_____	_____	_____	_____

My past experience with my dentist can be described by:

Other doctors I see include (gynecologist, podiatrist, psychiatrist, neurologist, cardiologist, orthopedist, etc.):

Name (Doctor)	Address	Phone/Email	Services Received (by this doctor)	Comments
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Other health care service providers I see (have seen) include (physical therapist, occupational therapist, speech therapist, counselor/therapist, social worker, etc.):

Name	Address	Phone/Email	Services Received	Comments
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

The Medications I currently take are:

Medication Name	Dosage & when taken (time of day)	Prescribed for?	Physician prescribed by?	Effects (on me)

In the past, I have been prescribed the following medications:

Medication Name	Dosage & when taken (time of day)	Prescribed for?	Physician prescribed by?	Effects (on me) and when STARTED & STOPPED!

Medications I would like to or must avoid and why:

Medication Name	Reason for Avoiding	Prescribing Doctor

The pharmacy I prefer using is:

I never want to use the following doctors or health care service providers:

My allergies include:

I use the following equipment to help with my vision, hearing and/or other needs:

Regarding caring for my special equipment, I need help to:

I have a history of seizures. YES NO

If "YES", my seizures are best described as follows

Frequency: _____

Type: _____

Description:

Before I have a seizure I:

After I have a seizure I:

Operations/conditions I have had in the past include:

My sleeping habits:

Other important medical information (genetic testing, immunizations, birth control, etc.):

Chapter Twelve: Personal Care

Height

Weight (date as of)

Clothing Size -
TOP

Clothing Size -
BOTTOM

Shoe Size

I appreciate being assisted with the following personal care needs:

I can independently do the following personal care tasks:

It helps if someone reminds me to do the following personal care tasks:

I am used to using the following personal care items:

Typically, my personal care routine includes:

My favorite clothes (including hats, shoes, etc.) to wear include:

Chapter Thirteen: Financial Information

My Social Security Number: _____ - _____ - _____

My Social Security Card is attached (a copy). Yes No

The Representative Payee (name, address and phone) is:

Name Address Phone Number

I receive SSI YES NO Amount: \$ _____

I receive SSDI (own record) YES NO Amount: \$ _____

I receive SSDI (DAC/Parent record) YES NO Amount: \$ _____

Medicaid Number: _____

My Medicaid Information is attached (a copy). YES NO

Medicare Number: _____

My Medicare Card is attached (a copy). YES NO

I have the following private insurance (i.e. health, dental, life, other):

Type of Insurance	ID #	Name of Company
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Additional income and/or assistance(s) information is as follows:

The following are bank accounts I have in my own name NOT Special Needs Trust, but including the Representative Payee Account that receives my SSI and/or SSDI:

Type of Account (i.e. checking, savings, etc.)	Name on Account	Account #	Bank Name	Bank Location & Phone Number
--	-----------------	-----------	-----------	---------------------------------

My personal investment and earned/working income is from:

My average paycheck amount is: _____

I use my earned paychecks for:

I do my own banking.	YES	NO
I am able to "make change".	YES	NO
I understand the <u>value</u> of <u>money</u> .	YES	NO
I am able to use my own money wisely.	YES	NO
I need the help with the following:		

Supplemental Funds - What to spend it on?

How often?

How much?

My tax information:

Accountant's Name

Accountant's Address

**Accountant's Phone
#/Email**

I can do my own taxes:

Yes

No

Chapter FIFTEEN: People Who Can Assist Me

I have the following Case Manager:

Agency's Name

Agency's Address

Agency's Phone # & Email

I have a 3RD Party Special Needs Trust:

Yes

No

My Trustee is:

Trustee's Name

Trustee's Address

Trustee's Phone # & Email

I have a 1ST (SELF Settled) Special Needs Trust:

Yes

No

My Trustee is:

Trustee's Name

Trustee's Address

Trustee's Phone # & Email

**I am the beneficiary of
other estate plan
documents (Will(s) &/or
Trust(s)), Insurance
Policies, IRAs, 401ks,
Pensions, etc.:**

Yes

No

Information/Explanation:

My Attorney(s) whom you may contact regarding my Special Needs Trust(s):

Attorney's Name

Attorney's Address

Attorney's Phone # & Email

I am my OWN Guardian: YES NO

My Guardian is (guardianship papers should be attached):

Guardian's Name

Guardian's Address

Guardian's Phone # & Email

Type of guardianship: Person

Estate

Limited

Plenary (Full)

If Limited, explain what limited to:

State/County of guardianship: _____

(Remember to attach a copy of the Court Order AND a copy of the most recent Annual Report.)

My Successor Guardian(s) is(are):

Successor Guardian's Name

Successor Guardian's Address

Successor Guardian's Phone/Email

My Agent for my Power of Attorney for Property is:

Agent's Name(Power of
Attorney - Property)

Agent's Address
(Power of Attorney - Property)

Agent's Phone #/Email
(Power of Attorney - Property)

My Successor Agent for my Power of Attorney for Property is:

Successor Agent's Name
(Power of Attorney - Property)

Successor Agent's Address
(Power of Attorney - Property)

Successor Agent's Phone
#/Email
(Power of Attorney - Property)

My Agent for my Power of Attorney for Health Care is:

Agent's Name
(Power of Attorney - Property)

Agent's Address
(Power of Attorney - Property)

Agent's Phone/Email
(Power of Attorney - Property)

My Successor Agent for my Power of Attorney for Health Care is:

Successor Agent's Name
(Power of Attorney - Health)

Successor Agent's Address
(Power of Attorney - Health)

Successor Agent's Phone/Email
(Power of Attorney - Health)

(Remember to attach a copy of both the Powers of Attorney for Property & for Health Care)

I have a Living Will. YES NO

***If yes, you can find the original at:* _____**

(Remember to attach a copy of the Living Will)

I have a Will. YES NO

***If yes, you can find the original at:* _____**

(Remember to attach a copy of the Will)

I have made the following funeral arrangements (burial, cemetery plot, cremation , financial plan, type of service) and/or I have the following preferences:

Chapter SIXTEEN: Some Final Thoughts

Other information about me:

One thing I would like you to know about me, it is:

Things my parents/guardians would like you to know:

Some of my future hopes and dreams include the following:

Some of my parents/guardians hopes & dreams for me include the following:

Attorneys & Staff

Brian Rubin, a former IRS Agent and former IRS Estate Tax Attorney, has been a practicing attorney in private practice since 1978. He is the parent of three children, one of whom, Mitchell, has Autism. Brian's law practice, since 1982, when Mitchell was one year old, has been dedicated to serving the legal and future planning needs of his fellow families of children and adults with intellectual disabilities, developmental disabilities, and/or mental illness. Brian has been elected as a Fellow of the American College of Trust and Estate Counsel (ACTEC), and has received the Martindale-Hubbell AV® Preeminent™ Rating. He is President-Elect of the Special Needs Alliance, the national, non-profit, association of experienced special needs planning attorneys (membership is by invitation only), served on the Special Needs Law Section Steering Committee, of the National Academy of Elder Law Attorneys, was a Charter Member of the Academy of Special Needs Planners, and is a Faculty Member and Text Book Author for the Illinois Institute for Continuing Legal Education (IICLE) on the topic of special needs legal and future planning. Brian is a Past Chairman of the State of Illinois Statewide Advisory Council on Developmental Disabilities, Immediate Past Chairman of the State of Illinois Autism Task Force (2005-2015) established by the Illinois Legislature in 2005, serves as a member of the State of Illinois Guardianship & Advocacy Commission, served on the State of Illinois Department of Human Services Office of Inspector General Quality Care Board, among many other State of Illinois Committees and Commissions. Brian is the Immediate Past President of The Arc of Illinois; has been a member of the Board of Directors of Clearbrook (an organization serving more than 8,000 individuals with intellectual and/or developmental disabilities, including his son, Mitchell) since 1990, is Immediate Past Chairman of the Board of Directors of the Special Leisure Services Foundation, the foundation supporting the Northwest Suburban Special Recreation Association (NWSRA), served as the founding Chairman of the Board of Directors of the Foundation of The Special Education District of Lake County (SEDOL Foundation), served on the Board of Directors of KESHET (Jewish Parents of Children with Special Needs), serves on the Advisory Council of Encompass (Encompass in partnership with Jewish Child & Family Services, Jewish United Fund, JVS Chicago, JCC Chicago, Keshet, and The Center for Enriched Living and Center for Independent Futures, seeks to provide adults with I/DD a full array of financially sustainable, community-based services and supports), served on the Board of Directors of Pact, Inc., now known as DayOne Pact, the Independent Service Coordination Agent for individuals with intellectual and/or developmental disabilities living in DuPage, Kane and Kendall Counties Illinois, as well as serves as Trustee of Special Needs Trusts, and serves as Guardian, and served on the Board of Directors of Northpointe Resources, also an agency serving individuals with intellectual and/or developmental disabilities. Brian feels the tremendous responsibility of not only being the parent of a child with special needs, but also as an attorney with the knowledge and ability to assist others in special needs future planning... needed to secure the future of children and adults with special needs.

Benjamin (Benji) Rubin, Brian's youngest son, Mitchell's "little/big" brother, graduated from the University of Illinois College of Law, Magna Cum Laude, received his undergraduate degree from Northwestern University, and currently is pursuing his Graduate Law Degree, an LLM (Tax), at Northwestern University. Benji, a partner in the law firm, joined the practice in 2010. Benji is a member of the Academy of Special Needs Planners, a member of the Special Needs Alliance, is Vice Chairman of the American Bar Association Special Needs Planning Committee, serves as the President of SIBS (Supporting Illinois Brothers and Sisters), the Illinois chapter of the national Sibling Leadership Network, is a member of the Board of Directors of The Arc of Illinois, is a member of the Clearbrook Associate Board, and serves on the Advisory Council of Encompass (Encompass in partnership with Jewish Child & Family Services, Jewish United Fund, JVS Chicago, JCC Chicago, Keshet, and The Center for Enriched Living and Center for Independent Futures, seeks to provide adults with I/DD a full array of financially sustainable, community-based services and supports), and is a member of the Board of Directors of the SEDOL (Special Education District of Lake

County) Foundation. Benji is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE). Having Mitchell as a brother profoundly shaped who Benji is today, and thus the type of law he chose to practice. His personal experiences as a sibling offer a unique perspective into the responsibilities that come with caring for a sibling with special needs. Now, as an adult, those sometimes present and future responsibilities he will share with his older sister regarding his brother's care are a concern that he shares with all brothers and sisters of individuals with special needs.

Judith L. Smith - Attorney Judie Smith has been licensed to practice law in the State of Illinois since 1985. She has been an associate attorney with Brian Rubin since 1996. Judie's practice, since 1996, has been limited to special needs estate planning and administration for families of individuals with special needs. Judie has handled countless adult guardianship matters for clients in Cook, Lake, McHenry, DuPage and Kane Counties. Her courtroom experience includes preparation and court approval of Medicaid "Pay Back" Trusts (also referred to as "OBRA '93 Trusts" and/or "d4A Trusts", preparation and court approval of trust and estate budgets, as well as preparation and approval of trust and estate annual accountings and annual reports. Judie is a member of the Special Needs Alliance. Judie is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE).

Melanie B. Hoffman - Attorney Melanie Hoffman has been licensed to practice law in the State of Illinois since 1993. She began her career with the Office of the Cook County Public Guardian, working on behalf of abused and neglected children, and subsequently working in the Disabled Adult Division, responsible for estate administration and guardianship matters. Melanie left the Office of the Cook County Public Guardian to become an associate of Brian Rubin in 1995. Melanie's practice was limited to estate planning, estate administration and guardianship for families of individuals with special needs. After a period spent raising her family, she renewed her affiliation with Brian Rubin in 2012. Melanie is an affiliate member of the Special Needs Alliance. Melanie is also a Faculty Member for the Illinois Institute for Continuing Legal Education (IICLE).

Nicole Rosenthal - Brian Rubin's daughter, and Benjamin's and Mitchell's "big sister" (and assistant mother) joined Rubin Law as office manager and legal assistant in 2001. Nicole's undergraduate degree is in nursing and is a Registered Nurse (RN/BSN). Nicole, as an older sibling, brings an unparalleled understanding of the day-to-day obstacles, and successes that her fellow families of individuals with special needs endure.

Karen Muschkat - Karen joined Rubin Law as a legal assistant in 2007. Karen has more than 20 years of extensive experience in the areas of estate planning & estate administration.

Linda Rubin - Brian Rubin's wife, joined Rubin Law as a legal assistant in 2001. Linda, as Mitch's Mom, offers an experienced point of view as someone who has lived through all the trials & tribulations that fellow families of individuals with special needs weather.

Carmen Cuzmanko - Carmen joined Rubin Law in 2015 as a legal assistant. Carmen is a parent of child with autism.

Mitchell Rubin - Brian Rubin's son, who has autism among other diagnosed special needs, also works at Rubin Law on Mondays, shredding documents and greeting clients, among other assigned tasks.



Special needs require special lawyers.

The Guidance and Information Document For Future Care Providers and Trustees

BY BRIAN RUBIN

WHY DO IT, WHEN TO DO IT, WHAT IT SHOULD INCLUDE.

As parents of a child with special needs, you possess a vast amount of information and history about your child that no one else possesses. You have your thoughts and wishes for your child's future in your head. You know, in your heart of hearts, that no one else can truly understand your concerns, worries, and fears for what will happen to your child after you are gone.

You wish that your child with special needs will have a long, happy and enjoyable life. However, you pray that you live at least one moment longer than your child, so that you will not have to place the responsibility of caregiving upon others. You hope that you will always be there for your child.

As difficult as it is, you must consider the possibility that you may die before your child, or that you may become unable to care for your child during your lifetime, leaving the responsibility to others, whether court-appointed guardians, trustees of special needs trusts, trust advisors, trust protectors, and/or members of your child's micro board or other committee. (For purposes of this article, I will refer to all of those individuals, collectively, as the "future team.")

How do you communicate to this future team all that you wish them to know? How do you inform and educate this future team about your concerns, desires, hopes, wishes, and, yes, prayers as to the future life of your child?

Out of necessity, you have learned, over the years, how to navigate the complex maze of special education services available through your respective state programs, SSI, SSDI, Medicaid, and Medicare. However, the members of your child's future team may know little about these matters, little about the battles you have won and lost, of the dead ends and road-blocks that you may have encountered. After all, they have been busy with their own lives and concerns. Are they prepared to step into your shoes? To ensure the best for your child and your team, you have an obligation, a duty, to educate your future team now, and to leave a road map for the future.

You can't ask the members of your future team to accompany you to every event and every meeting. How do you provide your future team members with the information and guidance that they need?

Since memories are faulty, many parents choose to reduce this information and guidance to writing, in a document that is updated periodically. Often such a document is referred to as a "letter of

intent." I choose to refer to it as "guidance and information" for the future team. There are many samples of such documents on the internet. Use any form you find as a guide, and prepare your own document on your own computer. That way, you can revise the document periodically, save it, and forward it.

What topics should be addressed in your document of guidance and information? First, the document should include a brief list of bullet points covering the essential items your team would need to know immediately in order to care for your child in the first 24 to 48 hours after you have passed away or become incapacitated. I refer to this as the executive summary. Next to some of the bullet points, you may want to place a note referencing more complete information on a subsequent page. While the staff who provides support for your child may know your child very well, they can get sick, go on vacation, retire, or quit, and these bullet points will be very, very important for fill-in or new staff, as they will for other members of the future team.

CONSIDER INCLUDING IN THIS EXECUTIVE SUMMARY:

- The time the bus comes – both for pickup and dropoff. (Include the driver's name and contact information.)
- Teachers' and aides' names, contact information, and your comments about them.
- Employers'/supervisors' names, contact information, and your comments.
- Agencies'/service providers' contact information.
- Names and contact information for doctors and other important medical personnel.
- Current medicines, dosages, and location (including locations of prescriptions and pharmacy).
- Medicaid, SSI, SSDI, and Medicare information. Provide both parents' social security numbers in addition to your child's number.
- Documentation of any private, employer, VA, or other group health insurance that covers your child. (Photocopy front and back of insurance cards.)
- Location of calendar showing your child's scheduled activities for the week.
- Important routines.
- List of buzz words to say or not say; suggestions on how to

continued on page 42

Special Needs Alliance

continued from page 41

respond to problematic behavior.

- Suggestions on ways to explain to your child what has happened, that is, your passing or incapacity.

Every time the document is revised, start with the date that it was prepared, and by whom it was prepared. Depending on your child's abilities, consider including your child in the process. You may also want to include your other children, even if they are too young to be trustees or guardians. I suggest reviewing and revising this document at least every year around your child's birthday, if not more often.

In addition to the bullet points, the document should include more complete information and documents about your child, which you should keep current. The following list is comprehensive, and will take time. Don't be overwhelmed! Start with what you can manage. You can add to it as time goes on. A thorough document would include:

- Legal name and any nicknames (noting your child's preference).
- Date and place of birth (noting the attached birth certificate).
- Height, weight, clothing sizes, shoe size as well as the location of clothing, including coats, hats, shoes and gloves.
- Color of hair and eyes (attach a current photograph).
- Documentation regarding Medicaid waiver programs in which your child participates.
- A list of all relevant accounts with financial institutions, whether titled in your child's name, the name of the trustee of your child's special needs trusts, the name of a representative payee, or a custodial account.
- Contact information for the trustee of any special needs trust; if you are a trustee, the successor trustee(s)' contact information.
- List of personal care needs for which your child needs assistance.
- Daily personal care routine for your child.
- A description of your child's favorite clothes (including hats, shoes, etc.).
- A copy of your child's voter registration card, if applicable.
- A copy of your child's driver's license, if applicable.
- Child's blood type.
- Current diagnoses, as well as the history of prior diagnoses, including the names of the physicians who made them.
- List and history of allergies.
- List of current medications (attach prescriptions) with history of prior medications, changes in dosages, including dates, when taken, prescribed by whom, when and why discontinued. Include generic names if the doctor is OK with substitution for brand names. List side effects. Include the history of combination of medications, that is, the cocktails. Make sure to remember to list medications and/or combinations of medications to avoid, and why.
- List current doctors (attach contact information) as well as a history of prior doctors. For prior doctors, explain why each relationship

ended. Include specialists, dentists, eye doctors, gynecologist, podiatrist, psychiatrist, neurologist, cardiologist, and orthopedist. Also include other health care service providers such as physical therapists, occupational therapists, speech therapists, and social workers, etc. Do not forget to discuss doctors or health care service providers never to be used again, and the reasons for their exclusion.

- List and history of surgeries, diseases, medical conditions, and other important medical information (such as genetic testing, immunizations, and birth control). Include a history of seizures, if applicable, as well as the frequency, type, and description, the signs that a seizure is imminent, what to anticipate and what procedures to follow after a seizure.
- List of equipment to help with vision, hearing and/or other needs.
- Family tree (include nicknames). If possible, attach birth, death, and marriage certificates, as well as information on divorces.
- Medical history of the immediate family.
- List of individuals outside of the family whom your child may speak about, such as past aides, teachers and friends. Provide contact information to the extent it is relevant and appropriate.

IN ADDITION TO THE FOREGOING, YOU SHOULD PROVIDE INFORMATION REGARDING:

- Guidance on the best means of communication with your child and any communication tools.
- Mobility tools/means.
- Daily care, needs, activities, behaviors, habits and routines.
- Night time care, needs, behaviors, habits and routines.
- Stress and transition times as well as techniques to help your child through those times.
- Support systems and/or individuals as well as possible resources, including individuals and organizations.
- Special diet requirements, as well as food likes and dislikes.
- Friends... and those who are definitely not friends. Explain these relationships and include contact information.
- Social activities that your child likes and/or prefers as well as those that are definitely not liked.
- Educational history, including schools, programs, copies of last few years' IEPs, MDCs, and psychological evaluation/reports (older ones too, if available). If your child is under the age of twenty-two, include transition plan(s) and other plans for when he or she leaves special education. A copy of the last psychological evaluation/reports and IQ or comparable tests should be attached (if applicable). Copies of older ones should be attached if available.
- History of employment, day programs, residential programs and/or your thoughts about future programs. If your child is no longer in school and not working, then describe programs or activities in which your child participates during the day. Include past experiences with employment, volunteer work and/or day programming.
- If your child is employed, or you anticipate that your child will

be working in the future, detail what you envision for the future competitive employment, supported employment, or sheltered employment (workshop). If employed, attach correspondence, reports, and/or plans from supported employment or sheltered employment for at least the last three years.

- If your child is living in a group home or a facility, attach correspondence, reports, and plans from the agency or organization for at least the last three years.
- Religion and religious activities that are enjoyed or not enjoyed by the child, and again, your thoughts and wishes for the future in this area.
- How your child's income is usually spent.
- Child's ability or lack of ability to handle banking.
- Child's money skills, such as the ability to make change and understand the value of money.
- Child's and trust(s)' tax returns and information, as well as accountant's contact information.
- Funeral arrangements for your child, and your wishes in this regard.
- Your child's most successful means/methods of learning and remembering.
- What makes your child happy, sad, or upset. Discuss warning signs that your child is getting upset. Provide examples of the most successful ways to help your child through that emotion, and to help him or her calm down.
- Activities your child enjoys.
- Activities your child does not enjoy.
- Social settings that are difficult for your child.
- What might scare your child.
- How to best to prepare your child for scheduled events.
- How best to help your child through changes to scheduled and/or anticipated plans.
- How best to help your child deal with a loss, such as the loss of a family member, loss or departure of staff, loss of a friend, and even the loss of a job.
- What things motivate your child.
- How best to acknowledge your child accomplishing a task, or for appropriate behavior.
- How best to react if your child makes a mistake or fails at task.
- How best to react and help your child when your child is frustrated.
- What personal possessions are very important to your child.
- Your child's habits and routines, both during the day and in the evening.
- Activities your child likes (or dislikes) to do, whether with assistance, or on his or her own without assistance.
- People your child enjoys being with and those your child does not enjoy being with.
- Favorite vacations, and those never to try again.
- Exercise activities that your child enjoys.

• Current and past history of recreational activities and participation, including programs, organizations, and your child's preferences, likes and dislikes.

- Your child's abilities, including household tasks such as food preparation, whether on his or her own or with assistance.
- Food preferences and dislikes; preferred restaurants; special dietary requirements and food allergies.
- Events your family celebrates, such as birthdays, holidays (including religious, ethnic and cultural), and anniversaries. Describe the extent and nature of your child's participation in these events.
- Your thoughts on your child's future living arrangements, including geography, housemates, sharing of bedroom, possibly pets.
- Description and location of your estate planning documents, including, but not limited to wills, living trusts, powers of attorney, and special needs trusts as well as any guardianship documents and/or powers of attorney executed by your child. In doing so, make note whether your third party special needs trust is the beneficiary of the estate planning documents of other family members or individuals who wish to provide for your child. Such documents would include their wills and trusts as well as beneficiary designations under life insurance policies or qualified plans. Maintain a schedule all of your assets including those that don't pass through your will or probate, such as insurance policies, qualified plans, IRAs and annuities. Make sure to include the contact information for your special needs planning attorney.
- Your appointment by the court, if applicable, as your child's guardian, attaching copies of all court orders, accountings, and reports. Include the contact information for the attorney who has represented you in the guardianship.

Finally, remember that this is your document. No two children are the same. Don't limit yourself to somebody's form found on the internet, or even to the form received from your special needs planning attorney. Consider creating a video or audio of your thoughts. Ultimately, written words may be inadequate to express your feelings as parents of a child with special needs. •

Brian Rubin is an Illinois attorney and the father of a thirty year old son with autism. He has practiced law since 1976. His firm's practice is limited to special needs future planning for his fellow families of individuals with special needs. He is Vice President of the Arc of Illinois, Co-Chair of the State of Illinois Autism Task Force, and past Chairman of the State of Illinois Advisory Council on Developmental Disabilities. You can read more about Mr. Rubin at his firm's website, www.SNFP.net. Brian serves on the Special Needs Law Section Steering Committee of the National Academy of Elder Law Attorneys, and also serves on the Board of Directors of the Special Needs Alliance, a national, non-profit organization of attorneys committed to helping individuals with disabilities, their families, and the professionals who represent them. Contact information for a member in your state can be obtained by calling toll-free 1-877-572-8472, or by visiting: www.specialneedsalliance.org.

Running START

First Steps for Writing the Letter of Intent

by Brian Neal Rubin J.D.
Special Needs Alliance

Lean LOI • Daily Routine

The letter of intent (LOI), though not a legal document, plays a central role in your child's special needs plan, putting its endless details into personal perspective. Distilling years of family experience, it's meant to ease a difficult transition by guiding future caregivers, guardians and trustees in the decision-making that will shape a loved one's life when parents are gone.

Families with special needs can be so overwhelmed by daily challenges that capturing lessons learned doesn't top their to-do list. It's also emotional, requiring them to envision a time when their child will be without them. But the LOI is too important to delay. At any time, an unforeseen accident could land you in the hospital, or worse, with others suddenly called upon to assume your responsibilities.

So here's a less daunting way to begin. Think about what you'd share with another family member if they needed to care for your child for a couple days while you were out of town. What would they need to know to maneuver 48 hours of caregiving? By concentrating on the basics, you'll construct what I term the "executive summary" of your LOI; a two-page list of bullets that can be consulted when there's no time to leaf through a notebook.

Begin by imagining what you'd share about any young child: Here's what she'll eat. This is what time he goes to bed. Then build on that with the extras required for a child with special needs. At a minimum, this "lean LOI" should include:

- ✓ Daily routine.
- ✓ Best ways to communicate with the child.

- ✓ How to manage behaviors.
- ✓ Hot button words to avoid.
- ✓ Names and contact information for teachers, aides, bus driver, social service providers and employer.
- ✓ Medical information including names and contact information for doctors and therapists, lists of medications and location of prescriptions and pharmacy.
- ✓ Health insurance coverage.

Make this a family affair. Bring everyone together around the kitchen table, including the child with special needs, if they are able to participate. Let the conversation flow freely and just start taking notes; you can fine-tune later. Siblings have a different perspective from parents and are often able to think of important details that mom and dad would overlook.

Once you have your "short document" composed, share it with anyone who's likely to need it in the future and keep a copy alongside your other important papers. Review and update it annually.

Over time, you can build on this foundation, and you may find it useful to cross-reference the bulleted with specific pages in the full LOI that you'll eventually create. A more complete LOI should capture your child's history, preferences, the texture of daily life and your aspirations for the future. Here's a partial list of additional information to include:

- ✓ Contact information for family members and friends.
- ✓ Complete medical history. Also include medical history of immediate family members.
- ✓ Description of current living situation and, if that will change when you are no longer the primary caregiver,



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your preference for alternative arrangements.

- ✓ Financial documents.
- ✓ Public benefits they are receiving—Medicaid, Medicare, SSI, SSDI. Include Social Security numbers for the child and both parents. Share tips for dealing with government bureaucracies.
- ✓ Local agencies through which they receive services.
- ✓ Legal documents, such as advance directives.
- ✓ Educational history.
- ✓ Employment history.
- ✓ Food allergies, likes and dislikes.
- ✓ Assistance required with personal care.
- ✓ Clothing sizes.
- ✓ Personality traits.
- ✓ Lessons learned and situations to avoid.
- ✓ Favorite things. Also explain what the child finds upsetting.
- ✓ Social activities.
- ✓ Pets.
- ✓ Hopes for the future.
- ✓ How to discuss a parent's death or incapacity.

There are many sample LOIs available on the Internet, but, I suggest that you use them with care. Each child is unique, and you'll almost certainly find that these templates fail to address matters of importance to your child or contain sections that are inapplicable. Just cross out the irrelevant portions and, recognizing that this is your document, make any necessary additions.

The LOI is an intimate document, containing much information that only family members can provide. As my wife and I wrote in our own LOI, "How do we tell you all about our son...his life, how to talk to him and get along with him, as well as our hopes and dreams for his future... all in a few pages? Impossible...but here goes."♥

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"Ask the Professional"?

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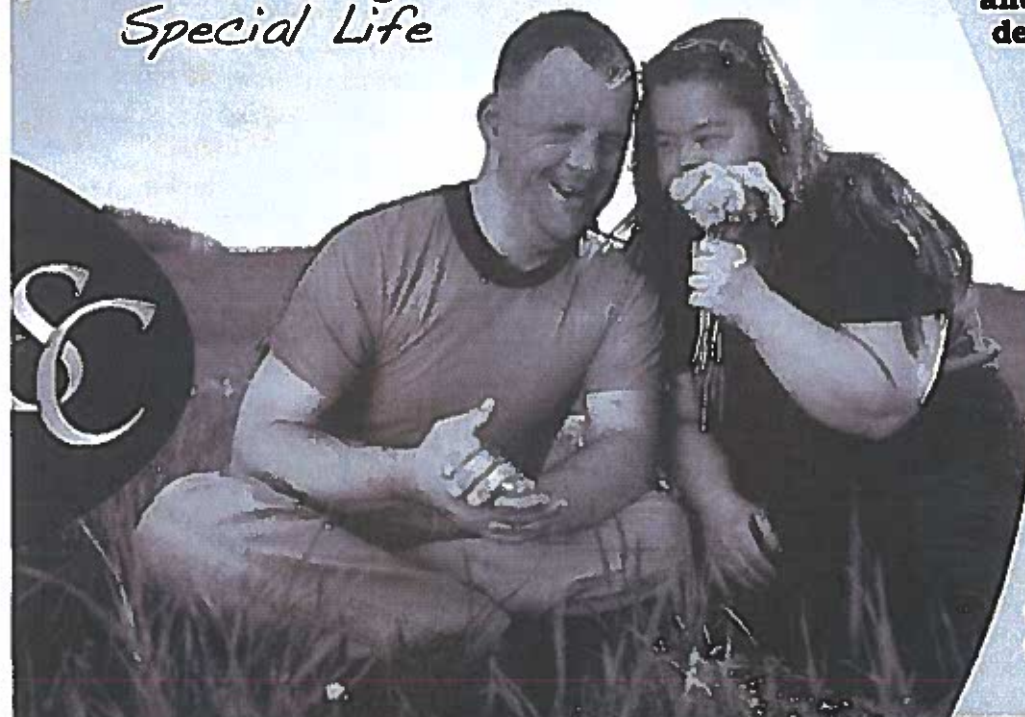
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Letters of Intent

(GUIDANCE AND INFORMATION FOR FUTURE
CARE PROVIDERS AND TRUSTEES)

What parent's often forget...

By Brian Neal Rubin J.D.

Attorney & Fellow Parent

As parents of children with special needs, we possess a vast amount of information about our child that no one else possesses. We also have our thoughts and wishes for our child's future, all, in "our heads": We all wish that our child with special needs will have a long, happy and enjoyable life, however, we pray that we live at least one moment longer, and that we will not have to place the responsibility upon others. But, as difficult as it is to think about our dying before our child with special needs, or in the alternative, as difficult as it may be to think about, due to our own disability, accident, or advanced age, our inability to care for our child, we must! We have that obligation to our child, to our other children, to our chosen future care providers, be they court appointed Guardians, Conservators, Trustees of our child's Special Needs Trust(s), "Trust Advisors" and/or "Trust Protectors"; and, if applicable, to members of our child's Micro-Board. For purposes of this article, I will refer to all of those individuals, collectively, as the "future team":

We have learned, over the years, the world of special education, how to navigate the complex maze of children and adult services available through our respective States, SSI, SSDI,

Medicaid, and Medicare. However, the members of the future team may know little about those matters, little about the battles you have won, and have lost, and of the dead ends and road-blocks that you may have encountered. Maybe they are aware of "bits and pieces"; but they have their own lives and concerns and most likely have retained little of what they may have "heard": How prepared are the members of the future team to "step into our shoes"; without losing or missing a step, without stumbling, into our world?

We are often told to communicate to the future team, all that we wish for them to know, our concerns, desires, hopes, wishes, and yes, prayers as to the future life of our child, by completing a document commonly referred to as a "Letter of Intent": a document that you will be periodically updating. There are many, many samples of such documents on the internet and also available from many organizations. I suggest that you use any such form only as a guide, and prepare your own "document" on your computer. That way, annually, or even more often, you can revise the document, save it, and forward it to your child's future team. Remember, not all of the sections in these suggested forms may be relevant to your child.

In my opinion what is missing from these available articles and forms is that in addition to the Letter of Intent document, is the need to also prepare a one or two page list of "bullet points" of what someone needs to know, immediately, to care for your child for the first 24 to 48 hours after they become responsible, possibly when you pass away, or unexpectedly become incapacitated. I refer to this as the "executive summary": Next to some of the bullet points you may want to reference that



here is more information on that "point" on page "X" of the full Letter of Intent document. That day that the unexpected event occurs and the "Future Team" is now in your home, with our child, they will not have the time to read your "book"... the complete Letter of Intent with all of the attachments. Consider including in this "executive summary":

What time the bus comes (includes driver's name, and contact information).

Current teachers and aide's names, contact information.

Current Employer/supervisor's names, contact information.

Current Agency's/Service Provider's contact information.

Current Doctor(s)' names and contact information.

Current medicines, dosages, and location (including locations of prescriptions and pharmacy information).

Current Medicaid, SSI, SSDI, and Medicare information.

Provide both parents' Social Security Numbers in addition to child's number.

Documentation of any private, employer, VA, or other group health insurance that covers your child.

Location of calendar of child's scheduled activities for the week.

Important routines, and "buzz" words to say or not to say.

Suggestions on how to respond to "behaviors".

How to explain to your child, "what has happened": that is, your passing.

suggest reviewing and revising the Letter of Intent and executive Summary every year on your child's birthday, if not more often. Remember that this is your document. No two children are the same. Don't limit yourself to a form you receive or found. Also, consider creating a video or audio of your thoughts, for written words are sometimes, simply, inadequate to express our feelings as parents of a child with special needs.

About Brian Rubin:

Attorney Brian Rubin has been a practicing attorney since 1976. For 31 years Brian's practice has been dedicated to Special Needs Legal & Future Planning for his fellow parents and families of children and adults with intellectual disabilities, developmental disabilities and/or mental illness. One of Brian's three children, Mitchell, now 32, has Autism. Brian serves on the Board of Directors of the Special Needs Alliance, the national, not for profit, association of attorneys who concentrate their practices in Special Needs Legal & Future Planning, served as Chairman of the State of Illinois Department of Human Services Statewide Advisory Council on Developmental Disabilities, serves as a Commissioner on the State of Illinois Guardianship and Advocacy Commission, has served on the State of Illinois Department of Human Services' Quality Care Board, which monitors operations, policies, and procedures of the Department of Human Services' Office of the Inspector General, serves as Co-Chairman of the State of Illinois Task Force on Autism, established by the Illinois legislature, is President of The Arc of Illinois, in addition to serving on the Boards of a number of other not for profit agencies serving individuals with intellectual disabilities, developmental disabilities, and/or mental illness. Brian serves on the faculty of the Illinois Institute for Continuing Legal Education on the topic of Special Needs Legal & Future Planning.

MetLife Center for Special Needs PlanningSM works with national non profits and individuals to help support the mutual goal of helping individuals with special needs. The Center is dedicated to helping families plan for the future of dependents with special needs. Helping you answer those questions, directing you to the right resources, and just being there as a resource and advocate for you, is an important part of what we do. If you'd like to find out more, or you'd like to be referred to a local MetLife Special Needs Planner, please call 1-877-638-3375, or visit our website at www.metlife.com/specialneeds.

MetLife does not provide tax or legal advice. Please consult your tax advisor or attorney for guidance.



'Alone we can do so little;
together we can do so much.'

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