

parenting

# specialneeds

magazine

*Parent*  
**Perspectives &  
Child Behavior**

*Financial*  
**GAME  
PLAN:**  
*Milestone Based Guide*





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Jan: Feb 2014

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# 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." ♥

Have a question for "Ask the Professional"?

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# SPECIAL CONSIDERATIONS

**Practice limited to “Special Needs Legal and Future Planning” for our fellow Illinois families of individuals with intellectual disabilities, developmental disabilities, and/or mental illness.**

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

## **ABOUT THE STAFF OF RUBIN LAW... a true family practice...**

**Attorney Brian Rubin, a practicing attorney since 1976**, 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 is the President of The Arc of Illinois; has been a member of the Board of Directors of Clearbrook (serving more than 3,500 individuals with developmental disabilities) since 1989; is a member of the Board of Directors of Pact, Inc. (PAS/ISC Agent for DuPage County, also available to serve as Trustee of Special Needs Trusts, as well as available to serve as Guardian); is Chairman of the Board of Directors of the SLSF, the foundation supporting the Northwest Suburban Special Recreation Association (NWSRA); served as the founding Chairman of the Board of Trustees 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); served on the Board of Directors of Northpointe Resources; serves on the Board of Directors 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 & Text Book Author for the Illinois Institute for Continuing Legal Education (IICLE). Brian is also the Past Chairman of the State of Illinois Statewide Advisory Council on Developmental Disabilities; Co-Chairman of the State of Illinois Autism Task Force since it was 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; served on the State of Illinois Department of Human Services, Division of Developmental Disabilities Strategic Plan Team; served on the State of Illinois Disabilities Services Advisory Committee (The State of Illinois “Olmstead” Committee); and served on the State of Illinois, Department of Human Services, Division of Developmental Disabilities Quality Committee, among many other State of Illinois Committees and Commissions.

Brian is a former IRS Agent and a former IRS Estate Tax Attorney. Brian served by appointment on the American Bar Association’s Sub-Committee on “Special Needs Trusts and Other Protective Vehicles”. Brian has served by appointment of the President of the Illinois State Bar Association on that Association’s “Section Council” on Estate Planning, Probate and Trust Law. Brian also has served, by appointment, on that Association’s “Standing Committee” on the mentally disabled. Brian served three, four year terms, twelve years, as an elected Village Trustee in Buffalo Grove, Illinois (population 45,000) and was the founder of and served as Chairman of the Buffalo Grove Commission for Residents with Disabilities. Brian is a Past President of the Rotary Club of Buffalo Grove and has also served as an Assistant District Governor for Rotary District 6440.

Brian sincerely feels that Mitchell has allowed him, his wife, Linda, as well as “big sister/assistant mom” Nicole and “little/big brother” Benjamin, to better appreciate what is truly important in life... and what is...maybe.. not so important. 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. While Brian wishes for Mitchell to have a long, healthy and enjoyable life, he often admits that he prays that he lives at least one moment longer than Mitchell...for that ultimately is the “Parent’s Prayer”...the desire not to ask anyone else to, or to have anyone else have to “take over” the enormous responsibility of caring for their child with special needs...as only a fellow parent could understand. Brian is a frequent author and lecturer on the topic of appropriate future planning for families of individuals with special needs.

**continued on other side...**

## continued from other side...

**Attorney Benjamin (Benji) Rubin**, Brian's youngest son, Mitchell's "little/big" brother, graduated from the University of Illinois Law School, Magna Cum Laude, and received his undergraduate degree from Northwestern University. Benji is a member of the Academy of Special Needs Planners, an associate member of the Special Needs Alliance, serves as the President of SIBS (Supporting Illinois Brothers and Sisters, the Illinois chapter of the national Sibling Leadership Network - affiliated with the Arc of U.S.), and serves on the Leadership/Steering Committee of the Supported Community Living Initiative, a joint venture of the Jewish Federation of Metropolitan Chicago, the Jewish Child and Family Services, and Keshet, regarding residential and day programming for adults with intellectual and developmental disabilities. 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.

**Attorney Judith L. 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.

**Attorney Melanie B. 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.

**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 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 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.

**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.