

# 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

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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. •

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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](http://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](http://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



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**T**he 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,



- 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"?

Send an email to:

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# News From The Center

*Information and Support for the Special Needs Community*

## MetLife

### 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"...  
1. Complete Letter of Intent with all of the attachments.  
2. 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's/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 Planning<sup>SM</sup> 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](http://www.metlife.com/specialneeds).

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

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