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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, <u>immediately</u>, 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



there 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 your 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'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.

I 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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