



## LETTER OF INTENT: A game plan for caring for your

### child in the future.

I have noticed that many parents of special needs children spend many hours with their kids – whether its homework, transportation, therapies or just family time. Often Mom does activities with her child which are vastly different from what Dad does. Their days are so full that often they do not have a chance to talk with each other about what exactly the other does. They just do it.

But what happens if one or both parents are not here? Who will care for your child. More importantly, how will you be assured that your child would receive the same level of care that you provide? That brings us to the *Letter of Intent*.

For many of us, thinking about our children's future is very emotional and burdensome. The Letter of Intent is designed to be a roadmap, or game plan of what a typical day in the life of your child looks like. It is not a legal document, but a guideline – for the courts, guardians, siblings – or anyone who is involved in your child's day to day life.

The letter of intent would include vital, concrete information about your child's physical, mental and emotional status. It should include medications, therapies, food allergies, other allergies, physicians (be sure to note which doctors your child likes and which they don't). Medical history is important, as is a copy of the IEP. You can include your wishes for your child's future, thoughts about marriage, children, religion, job training and also academic achievements.

The more you put into the Letter of Intent, the more others who may care for your child will know. Probably most important is medical history and authority (perhaps a medical power of attorney) to gain access to medical records.

By writing it all down, you give the future caregivers the opportunity to look into your mind and see what your desires for your child are. By documenting and sharing this information with others, future care givers may know what the important issues are, and also what services (public and private) work best for your child.

If your child is cognizant and has the ability for self-determining their future, please include them in this process. It might be a good idea for you to tell them what you have in mind).

It does not need to be a thick binder full of notes (although the more the better). It can be just a typed letter or a form (available from me), video, tape recordings, or even hand written (if you are a dinosaur like me). I advise parents to update on their child's birthday (use a pencil if you use a form, as things certainly will change). (I might mention here that parents are urged to do this for their typical children, as well).

Here are some things to consider putting into the *Letter of Intent*

**Vital Statistics:** Full name, social security number, place and date of birth, nicknames, medical information. If you can, get a State ID, or record their height, weight, blood type and a recent photo is also helpful.

**Emergency Contact Information:** Who would you call first. Family members, guardians, executors, trustees, advocates, any government contacts, therapists, financial planners, attorneys, accountants – practically anyone involved with your child and their future.

**Skills and Weaknesses:** List your child’s skills and weaknesses. Whether diagnosed (by a doctor) or not (parents’ intuition), this helps to view the larger picture. With this list, you can build a support network that includes services your child currently receives, those you wish they could receive; what their support network is. Some of the following may prove to be helpful for the future generations:

**Clothing:** This will probably need to be updated if your child is still growing. However, if they need adaptive clothing, please make a note so that they are comfortable in what they wear

**Behavior:** Are there any behavior challenges? If so, what interventions have worked in the past, what hasn’t? List all doctors, therapists, caregivers – this can ensure continuity in caring for your child.

**Medical:** Medications, what has worked and what has not. Dosages, where they are kept, which doctor prescribed them. Many parents use homeopathic medicines. Please list them as well. Anticipate any situation that can arise, and provide a person, service or intervention that can help.

**Social Skills:** Who is their best friend? Who don’t they like. Hobbies, sports, recreation, places, characters (such as “beanie babies” or cartoon characters). Where do they like to go? What do they do? Are they shy? Do they make friends easily or not at all? All of this is important.

**Financial Situation:** How and who will handle the insurance proceeds, be the payee for SSI, and other assets?

**Living Situations:** Some may be able to live independently, some in a group home, or somewhere in between. Any thoughts as to roommates, where, how much supervision is needed? Be sure to be clear in your wishes and thoughts.

**Education:** The IEP (Individualized Education Plan) is very important here (be sure to include a copy of the current IEP, as well as any evaluations by counselors and psychologists, etc. College? Make a note. Some of the most disabled children have gone on to receive graduate degrees and have contributed greatly to our society and culture. What are your thoughts? If you have a 529 college savings plan set aside for your child, we should discuss this separately.

**Daily Living Skills:** How well do they handle money? Do they spend to get friends; can they count the correct change coming back to them after a purchase? Can they cook, do laundry, be alone for extended periods of time. Whatever you have taught your child should be recorded so that it can be continued and fostered in the future.

**Adaptive Equipment:** Do they need a specialized computer, speech recognition technology, mobility devices....if your child needs specialized equipment, this should also be prominent on your list.

**Work:** Do you want your child to work; are they able? Please note any employment history, and transition or vocational plans that would be in place when your child graduates from high school.

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