

Running *START*

First Steps for Writing the Letter of Intent

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*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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