

Providing for a Child with Special Needs: The Importance of Declaring Your Intentions

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DESCRIPTOR

The "Letter of Intent" is an important part of a comprehensive estate plan for parents of a special needs child. It provides those who will carry out a parent's wishes with the context they need to fully apply the instructions laid out in wills, guardianship and trust documents.

BODY

What Would a Parent Do?

For people guiding the care of a special needs child in the absence of the child's parents, this is not as much a philosophical question as it is a daily challenge: How can a surrogate caregiver make a child's life most like the life the parents had desired? You can help your designated surrogates perform that task by spelling out your vision in a letter of intent and giving copies of that letter to important people in your child's life, both those who are actively involved now and those who might be called upon in the future.

TOPICS TO COVER

While there is no single right way to create a letter of intent, it helps to start by recognizing that you could be speaking to people who may not have an opportunity to ask follow-up questions for clarification or amplification. In that light, begin your letter by setting the scene for your readers in broad strokes: Describe your vision for your child's life; Lay out your understanding of your child's talents, capabilities and interests; Highlight your guiding principles for child-rearing in general as well as for providing special-needs care and support. This can provide future caregivers valuable context for specific instructions and help set the tone for the more specific elements of your vision to follow. After you introduce your intentions, address each of these topics in detail as they relate to your child's needs and your expectations:

• Family life, significant relationships and important contacts. Think about immediate and extended family relationships your child is exposed to today: siblings, grandparents, aunts and uncles and cousins. How do you support these relationships at present (Holiday visits? Shared vacations? Sleep-overs? Extended family dinners?); how would you like surrogates to do so in the future? Consider relationships with neighbors, friends, parents and others outside your family circle. Identify those worth maintaining. Outline practical maintenance steps for your surrogates. Consider the professionals in your child's life: teachers, classroom aides, tutors, therapists and clinicians. Some of these relationships may transcend boundaries and could add value to your child's life if they were continued.

• Education: Current plans and future goals. If your child is receiving special services from a public school district, he or she is likely to be covered by an Individualized Education Program, or IEP. IEPs are usually created only after a great deal of discussion involving parents, educators and independent experts. IEPs are generally revisited yearly and revised as circumstances change. You can facilitate future IEP discussions by communicating your procedural tactics and objectives to your surrogates. (Keep in mind that a designated surrogate who was not previously involved in the IEP process may also benefit from basic background information on the specialized language and procedures involved).

Your letter of intent should look beyond the IEP process by addressing how far on the educational ladder you see your child progressing. Higher education or conservatory training may be realistic aspirations. How do they fit with your vision for your child? What about technical training and commercial skills development—what roles do you think they might play? Do you have any specific schools, programs or vocational directions in mind? What about any preferences your child may express—what weight should they be given? These questions can be addressed in a letter of intent, along with suggested deployment of any discretionary financial resources.

- Residence and living arrangements. The top three priorities for special needs children, like almost everyone else, are: Location! Location! Location! Your letter of intent should communicate the important parameters for the choice of location: proximity to friends and family and accessibility to resources such as schools, libraries, recreation, medical care and therapy. Also discuss your beliefs about independent living and your child's capability for managing his or her daily life.
- Employment and occupational training plans. Many parents have strong opinions about occupational outcomes for their children. Your letter of intent is your forum for outlining your intended outcome and showing a path to achieve it. Many children develop strong opinions about their own futures and some parents use the process of drafting a letter of intent to build a consensus with their child and demonstrate their support for their child's choice of direction.
- Management of behavior. Parents should articulate principles they follow in matters of child rearing and discipline. This discussion could include behaviors that need extra watching and include forms of direction you've learned to be effective or ineffective with the child. If you have explicit preferences about sanction and punishment, you could spell them out.
- Management of chronic conditions. Children may have strong relationships with pediatricians, dentists, clinical specialists and therapists. Use your letter of intent to show how these relationships can be sustained in your absence. How would you want your child's care plans as circumstances change, and would you take account of your child's preferences. If relevant, outline your beliefs and preferences for the possibility of heroic

and experimental medical interventions or the potential need for extraordinary life-saving measures.

- Social and recreational life of the child. Some children need significant control and direction over matters involving their friendships and recreational activities. If this applies to your child, outline principles you would follow if you were in control. If you expect your child will assume greater responsibility in the future, outline how you might create a transition plan. If your child is already capable of significant self-management in any area, endorse his or her autonomy.
- Religious and spiritual life of the child. Articulate preferences for your child's religious practices and observances. Put forth your desires for future religious education. If you give your child autonomy in this area, signal support for your child's preferences and expressions.

Other Considerations

Other points to consider about letters of intent:

- Share drafts of your letter with potential caregivers and surrogates. Assess their willingness/ability to follow directions you desire and negotiate resolutions to any differences of opinion in order to reach consensus for a course of action.
- Make multiple copies of your letter with original signatures.
 Give copies to those with significant responsibility for areas of concern. Leave copies with your estate lawyer and anyone with fiduciary responsibility over trust or estate assets.
- A letter of intent may not be a legally binding part of your estate plan, but provisions and expressions should be consistent with mandates you've expressed in trust, guardianship and estate documents. Some experts also suggest that your signature on the letter be formally witnessed and notarized.
- Review your letter of intent periodically to ensure that its expressions address current circumstances and remain consistent with your will, trust deeds and other estate documents.
- Many parents make an effort to involve their child (to the extent he or she is capable) in creating the letter of intent.
 Parents also extend the concept to create letters of intent covering nondisabled children as well, finding that it opens constructive channels of communication across the family.

Effective plans for special needs children may require financial wherewithal to support declarations of intent. I have tools to help draw up an effective financial plan to sustain your intentions; among them, a work sheet to develop a realistic budget. Creating a meaningful letter of intent to guide the care of your special needs child is an intricate task, and you must weigh a host of competing priorities. I can help you evaluate the demands and reach a workable solution.

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