

## **The Letter of Intent**

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by Richard W. Fee

What is the Letter of Intent? Simply put, the Letter of Intent is a document written by you (the parents or guardians) or other family members that describes your son or daughter's history, his or her current status, and what you hope for him or her in the future. You would be wise to write this letter today and add to it as the years go by, updating it when information about your son or daughter changes. To the maximum extent possible, it is also a good idea to involve your child in the writing of this Letter, so that the Letter truly "presents" and represents your child. The Letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

Even though the Letter of Intent is not a legal document, the courts and others can rely upon the Letter for guidance in understanding your son or daughter and the wishes of you, the parents. In this way, you can continue to "speak out" on behalf of your son or daughter, providing insight and knowledge about his or her own best possible care.

### **Why is it Important to Write a Letter of Intent?**

A Letter of Intent serves many purposes. First, it spells out in black and white your son or daughter's background and history and his or her present situation. It also describes your wishes, hopes, and desires for his or her future care and, where possible, describes your child's feelings about the present and desires for the future. While you are still living, the Letter can be used by your lawyers and financial planners to draft the proper legal documents (wills and/or trusts) to ensure your wishes are carried out. Once you are no longer able to take care of your son or daughter, due to death or illness — and this is the most important reason to write a Letter of Intent — the Letter gives your son or daughter's future caregivers some insight into how to care for him or her. It provides advice on possible alternatives for his or her care. If your child has a severe disability, caregivers will not have to waste precious time learning the most appropriate behavior or medical management techniques to use. If your child is used to doing things independently and only requires occasional assistance, the Letter can spell out exactly what is needed.

The Letter of Intent can describe this very concrete information and much, much more, including valuable information about the personality of your son or daughter — his or her likes, dislikes, talents, special problems, and strengths. Thus, the Letter is a crucial part of any life or estate plan, because it speaks both for and about the person with a disability and his or her family.

### **When Should Parents Write the Letter of Intent?**

The answer is a simple one. Start now. Start today. Procrastination is easy, when your health is good, the future looks bright, and there are a hundred other pressing tasks to be done. But none of us can predict the future. What will happen to your son or daughter, if something happens to you? Will your relatives, friends, lawyer, or the police know where to contact your son or daughter - and will that person know enough about your loved one to know what kind of care is needed and how best to provide it?

Writing the Letter of Intent now is a way to protect your son or daughter from unnecessary chaos and turmoil when he or she must depend upon someone other than you for the care and support that is necessary. The Letter of Intent helps pave your son or daughter's transition by giving future caregivers the information about him or her that they so vitally need.

Preparing the Letter is often an emotional experience for parents and their children. You will need self-discipline and motivation to work past the many painful questions and issues that must be addressed when considering your son or daughter's future.

### **What Information Goes Into the Letter of Intent?**

How can you summarize the life of a person you have watched grow and develop over many years? What can you say that will give insight into and perhaps touch the heart of a care provider who must suddenly assume some measure of responsibility for your son or daughter?

Basically, the procedures for developing a Letter of Intent are fairly simple. You can write the Letter out longhand, or you can use a computer or typewriter. Don't worry about perfect spelling or grammar; your major concern is that anyone who reads the Letter in the future can understand exactly what you meant and what you would like to see happen in your son or daughter's life. Begin by addressing the Letter to "To Whom It May Concern." In the first paragraph list the current names, addresses, and telephone numbers of the people who should be contacted if anything should happen to you (i.e., other children, case manager, your son or daughter's school principal or employer, lawyer, financial planner, priest, etc.). You might then briefly state the family history; include names, birthdates, and addresses of family members.

The Letter will then need to focus in upon seven potentially major areas of your son or daughter's past, present, and future life. Depending upon your child's needs, these areas may be: housing/residential care, education, employment, medical history and care, behavior management, social environment, and religious environment. You might begin by summarizing your son or daughter's background and present status in each of these areas. Then summarize your wishes, hopes, and desires for his or her "best" future, listing three or four options in each of these areas. Be sure to discuss your ideas with your son or daughter and to take into consideration his or her feelings on the future (more is said about this below). The worksheet shown at the end of this article is useful for this "future planning" step, which may require much thought and planning before you actually begin to write information into the Letter of Intent.

Take a brief look at the example below (marked "An Example for Writing a Letter of Intent"). This example focuses on only one of the major life areas— Housing/Residential Care — and illustrates how a person named Mrs. Sanders went about writing this section of her Letter of Intent for her son named Chris, a 35 year old man with developmental disabilities.

### **How Do I Involve My Son or Daughter in Writing the Letter?**

How much you involve your son or daughter in writing the Letter of Intent will depend in large part upon his or her age and the nature and severity of the disability. It is only fitting that young adults and adult children be involved in planning their own lives to the maximum extent possible. Many individuals have disabilities that do not prevent their full or partial participation in the Letter-writing process. Before involving your child, however, you, as parents, might want to talk first among yourselves about the content of the Letter and your ideas regarding your child's future. When you've agreed upon the basic information you feel should go in the Letter, discuss each area with your son or daughter. Ask for your child's input about his or her favorite things to do, what type of education has been enjoyable and what might be pursued in the future, what type of employment he or she enjoys or envisions. Equally crucial to discuss are your child's future living arrangements: How does your child feel about the options you are considering listing in the Letter of Intent?

It's important that your child realize that the Letter is not a binding, legal document; it is written to give guidance, not edicts, to all those involved in caregiving in the future. If you fear that your child will be upset by talking about a future that does not involve you as parents, then you may wish to make the discussion simply about the future — what will happen when your child leaves high school or a postsecondary training program, what your child wants to be or do in the next ten years, where he or she wants to live. You may be surprised to find that discussing the future actually relieves your child. He or she may very well be worrying about what will happen when you are no longer there to provide whatever assistance is needed.

Involving your child in discussing and making decisions about the future may be more difficult if the individual has a disability that severely limits his or her ability to communicate or to judge between a variety of options. You, as parents, are probably the best judges of how much — and how — you can involve a son or daughter with a severe cognitive disability. For these children, the Letter is especially critical; it will serve to communicate the vital information about themselves that they cannot.