

Parent's Wishes

Every parent's concern: What will happen to my child if I am not able to care for him/her? The challenge of planning for a child's future beyond the life of the parents can seem overwhelming. Even when the family has other children or family who are willing to take over the responsibility from the parents, problems may arise for two reasons:

1. They are not clear about the wishes of the parents and do not have the historical knowledge about the child to feel comfortable with the decisions they are required to make.
2. Laws and services change over time and the plans made by the parents may need to be revised for the child to receive maximum benefits from the system.

Preparing for the point in time when you, the parents, are unable to make critical decisions for your dependent child is a very complicated undertaking. You draw up a Will and Trust which does not have a negative impact on the services your child is entitled to receive from the government. A Will and/or Trust will not necessarily ensure that your wishes for your child are always considered. A Letter of Intent is a way to have your voice be heard beyond the time when you are no longer with your child.

A Letter of Intent is a document that you prepare to help the guardians, trustees and the courts interpret your hopes and desires for you child. It is not a formal "legal" document, but the courts will look to it for guidance in understanding your child and your wishes. The courts tend to favor the family's wishes as long as they are not illegal or immoral.

Because you are the one constant in your child's life, you can share information with professionals and others that can improve the quality of their work with your child. It will help them understand what works for your child and what does not work. It will also save you and your child's future guardian's time. Think of how often you have to repeat the same information to various service providers. Providing them with a single document that contained most of the information they needed would be very helpful.

It is important to note that writing a Letter of Intent forces you to discuss (often for the first time) the many concerns you have about your child and in some cases if they have any disabilities. This can be an emotional if not painful experience. Be aware of this and plan to work on the letter at a point in time when you are not feeling overwhelmed by your life. You may also find that you need to work on small portions of the letter over time or have some help in gathering portions of the documents.

This Letter of Intent is not a traditional letter. You do not write it and forget it. It is a living document that should be updated and added to on a regular basis throughout your life. You may want to set aside an anniversary date to review your letter every year, and make needed changes. At other times events will require the letter to be changed immediately, such as noting a bad reaction to a specific medication. When you need to make changes you may only need to rewrite that portion of the letter. Placing the information on a computer for easy updates is one way to keep the document current. If

you have to write or type your letter, organize it so that information which may need to be frequently updated is on a separate page from the information (such as family history, social security number etc.) that won't ever change. You may also separate information that can easily be shared (educational history, personal preferences, etc.) from more sensitive information (cash income, life insurance, etc.)

Whether you write it out in long hand, use a typewriter, or use a computer be sure to sign it and date it. Place it with your other important papers and let someone who can be trusted know of its existence.

Don't worry if you are not a skilled writer. This is not an English paper. This is a way to let people know what you want for your child, and what you are particularly concerned about for his/her future.

What follows are the general guidelines for writing a Letter of Intent.

The letter can be addressed to "To Whom it May Concern" or you may want to make it more personal by addressing it directly to your child. Depending on the severity of your child and any disabilities, this letter may be a continuing form of communication after you are gone. It will be Mom and Dad's Special Letter.

Each letter should cover the key areas of your child's life. You should describe what has happened thus far and express your desires for the future. The following topics should help you organize your thoughts:

1. Family History

- Where and when you were born
- Where and when you were raised
- Where and when you were married
- Something special about brothers, sisters, aunts, uncles, grandparents, etc.
- Special friends and relatives that your child knows and likes
- Description of your child's birth, when, where, your feelings, etc.

2. General Overview

- Brief overview of your child's life to date and your general feelings about the future

3. Education

- Summary of educational experiences and desires for the future education
- Regular classes, special classes, special schools, etc.
- Mainstreaming, etc.
- Types of educational emphasis, i.e. vocational academic, total communication, etc.
- Name specific programs, schools, teachers, if you know them

4. Employment

- types of work he or she might enjoy
 - open employment with supervision, sheltered workshop, activity center, etc.
 - companies that you are aware of that may provide employment in your community.
5. Residential Environment (in the future)
- live with relatives, specify relatives
 - if not relatives or if relatives pass away next friend or relative
 - your other options if child is disabled, i.e. group home in the same community, institution
 - specify size of group home or institution
 - describe best living arrangements – single room, etc.
6. Social Environment
- mention the types of social activities your child enjoys, i.e. sports, dances, movies, etc.
 - should your child have personal spending money and how should he or she spend it
 - mention favorite foods, eating habits, etc.
 - does your child usually have annual vacations with relatives, friends, church or charitable groups
7. Religious Environment
- specify religion
 - specify local churches
 - mention local ministers, priest, rabbis that are familiar with your child
 - ask for regular visits from church members/clergy, if possible, etc.
 - request that your child participate in church services and other activities as much as possible
8. Medical Care
- mention current medication being taken and the purposes of each
 - discuss the drugs that have and have not worked in the past and why
 - describe your feelings about the drug therapy program, etc.
 - (mention allergies, medical conditions/consideration, etc.)
9. Behavior Management (Support Needs)
- describe the current behavior management program that is being used
 - mention the other behavior management programs that have been tried and give the results

10. Final Arrangements

- describe your desires for your child's final arrangements and include information about:
 1. prearrangements, if any
 2. choice of funeral home
 3. cremation or burial
 4. cemetery
 5. monument
 6. church service

Please include any other information that you feel will help the future care providers in giving the best possible care and supervision. (For example does you child have preferences for colors, music, sleeping late, etc. What brings your child happiness or pleasure?)

The Letter of Intent should be placed in you special estate planning binder with all of the other relevant legal and personal documents concerning your child. Should anything happen to you, the future guardians and trustees will have the information that will guide them in understanding your child's unique history and will assist them in maintaining the quality and consistence of life which is essential to any child.

If you have any concerns or questions, please contact my office.

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