

Letter of Intent Form

How Parents can Communicate Their Wishes and Knowledge about Their Son or Daughter with a Disability to Future Caregivers

How can you, as a parent, be assured that your son or daughter will lead as complete a life as possible after your death? What can you do to make sure your hopes and aspirations are realized? Writing a letter of intent is a critical step in the planning process. This critical document permits parents to communicate vital information about their son or daughter to future caregivers.

Parents, you are the experts on your child. You receive a lot of important advice from professionals, but no one understands your son or daughter's needs and desires better than you. If you become incapacitated or die, it is vital that future caregivers have access to your knowledge.

In most cases, the future caregivers will be relatives. But even if these relatives are very close to your child, they may not be aware of important personal information. For instance, do the future caregivers know all the pertinent information about your child's medical history? Do they know the names, addresses, and phone numbers of all the professionals who serve your child? Do they know the names of professionals who you think should be avoided? Moreover, if these relatives die or move away, successor care-givers will need explicit information.

Although not a legally binding document, a Letter of Intent is an ideal format. It allows you to communicate your desires to future caregivers and therefore will prove invaluable to them. The letter assumes even greater importance if these future caregivers are out of state and do not see your child frequently, or if the ultimate caregiver will be a trust officer at a bank.

To write a Letter of Intent, just follow the guide, which covers vital details about what works well for your child in all of the major life areas: residential placement, education, employment, socialization, religion, medical care, final arrangements, and so on. Flexibility is important, so there should be several prioritized options listed under each heading. Possibly you will want to add some categories of your own to those listed in the guide, and you should feel free to make any adjustments necessary to meet the individual needs of your son or daughter.

Be sure to include enough information. For instance, if you write down a Social Security number, be sure to use the words "*Social Security Number*" so that someone reading the document after your death doesn't have to guess what those numbers represent. If you list your child's doctor, make sure to include his or her address and phone number. Also, using category headings similar to those in the guide may make it easier for anyone to find particular pieces of information.

If both parents are living, one of you may want to do the actual writing of the Letter of Intent while both of you will want to sign it. The letter can be typed or handwritten. It isn't an essay for school, and perfect grammar, spelling, or style are not the point. Your major

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concern is to make sure that your child will have a happy and meaningful life. Write clearly enough so that anyone who reads the letter in the future will understand exactly what you meant.

Some of the items we ask you to include in the Letter of Intent are discussed in my book, **Planning for the Future** (such as your child's finances, for example). If you don't have a copy of the book, just do your best. We can always make revisions later, either after we have talked or you have reviewed the book.

Each year you should take out the letter and review it to make sure it remains current. Choose the same date each year, perhaps your child's birthday, so you won't forget. Occasionally there will be a significant change in your child's life, such as a new residential placement or a bad reaction to medication, and the letter should be revised immediately if any such change occurs. Many clients keep the letter on a word processor so changes can be made more easily.

Here is the form template you can use...

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Letter of Intent

Written by:

Date:

(Relationship to the person with the disability—mother, father or both)

To Whom It May Concern:

Information About _____ (Father's name)

General information: List the father's full name, Social Security number, complete address, phone numbers for home and work, county or township, date of birth, place of birth, city/town/country where raised, fluent languages, religion, race, blood type, number of sisters, and number of brothers. Indicate whether he is a U.S. citizen.

Marital status: Indicate the father's marital status. If he is currently married, list the date of that marriage, the place the marriage took place, and the number of children from that marriage. Also list the dates of any previous marriages, names of other wives, and names and birth dates of children from each marriage.

Family: List the complete names of the father's siblings and parents. For those still living, list their addresses and phone numbers, as well as pertinent biographical information.

Information About _____ (Mother's name)

General Information: List the mother's full name, Social Security number, complete address, phone numbers for home and work, county or township, date of birth, place of birth, city/town/country where raised, fluent languages, religion, race, blood type, number of sisters, and number of brothers. Indicate whether she is a U.S. Citizen.

Marital status: Indicate the mother's marital status. If she is currently married, list the date of that marriage, the place the marriage took place, and the number of children from that marriage. Also list the dates of any previous marriages, names of other husbands, and names and birth dates of children from each marriage.

Family: List the complete names of the mother's siblings and parents. For those still living, list addresses and phone numbers, as well as pertinent biographical information.

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Information About _____ (Your son or daughter's name)

General Information

Name: List the full name of your son or daughter. Also list the name he or she likes to be called.

Numbers: List your child's Social Security number, complete address, county or township, telephone numbers for home and work, height, weight, shoe size, and clothing sizes.

More details: List your child's gender, race, fluent languages, and religion. Indicate whether your child is a U.S. citizen.

Birth: List your child's date and time of birth, as well as any complications. List your child's birth weight and place of birth, as well as the city/town/country where he or she was raised.

Siblings: List the complete names, addresses, and phone numbers of all sisters and brothers. Which ones are closest to the person with a disability—both geographically and emotionally?

Marital status: List the marital status of your son or daughter. If married, list the spouse's name, his or her date of birth, the names of any children, and their dates of birth. Also list any previous marriages, as well as the names, addresses, and phone numbers for the spouses and children from each marriage.

Other relationships: List special friends and relatives that your child knows and likes. Describe the relationships. These people can play an invaluable role, especially if the trustee resides out-of-state.

Guardians: Indicate whether your child has been declared incompetent and whether any guardians have been appointed. List the name, address, and phone number of each guardian and indicate whether that person is a guardian of the person or guardian of the estate, plenary or limited.

If successor guardians have been chosen, list their full names, addresses, and phone numbers. Even if your child has no guardian, it is often wise to state in the Letter of Intent your wishes about who you want to act as guardian if one is needed in the future. Make sure you have spoken with them.

Advocates: List the people, in order, who you foresee acting as advocates for your child after your death. Make sure you have spoken with them.

Trustee: Indicate whether you have set up a trust for your child and list the full names, addresses, and phone numbers of all the trustees.

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Representative payee: Indicate whether your son or daughter has or needs a representative payee to manage public entitlements, such as Supplemental Security Income or Social Security.

Power of attorney: If anyone has power of attorney for your son or daughter, list the person's full name, address, and phone number. Indicate whether this is a durable power of attorney.

Final arrangements: Describe any arrangements that have been made for your child's funeral and burial. List the full names of companies or individuals, their addresses, and phone numbers. Also list all payments made and specify what is covered. In the absence of specific arrangements, indicate your preferences for cremation or burial. Should there be a church service? If the preference is for burial, what is the best site? Should there be a monument? If cremation is the choice, what should be done with the remains?

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Medical History and Care

Diagnoses: List the main diagnoses for your son or daughter's condition, such as autism, cerebral palsy, Down syndrome, epilepsy, impairment due to age, learning disorder, an intellectual disability, neurological disorder, physical disabilities, psychiatric disorder, or an undetermined problem.

Seizures: Indicate the seizure history of your son or daughter: no seizures; no seizures in the past two years; seizures under control; seizures in the past two years, but not in the past year; or seizures currently. Does anything act as a "trigger" for increased seizure activity?

Functioning: Indicate your child's intellectual functioning level (Mild, moderate, severe, profound, undetermined, etc.).

Vision: Indicate the status of your child's vision: normal, normal with glasses, impaired, legally blind, without functional vision, etc. List the date of the last eye test and what was listed on any prescription for eyeglasses.

Hearing: Indicate the status of your child's hearing: normal, normal with a hearing aid, impaired, deaf, etc.

Speech: Indicate the status of your child's speech: normal; impaired, yet understandable; requires sign language; requires use of communication device; non-communicative, etc. If your child is non-verbal, specify the techniques you use for communication.

Mobility: Indicate the level of your child's mobility: normal; impaired, yet self-ambulatory; requires some use of wheelchair or other assistance; dependent on wheelchair or other assistance; without mobility, etc.

Blood: List your child's blood type and any special problems concerning blood.

Insurance: List the type, amount, and policy number for the medical insurance covering your son or daughter. What is included in this coverage now? Indicate how this would change upon the death of either parent. Make sure you include Medicare and Medicaid, if relevant.

Current physicians: List your child's current physicians, including specialists. Include their full names, types of practice, addresses, phone numbers, the average number of times your child visits them each year, the total charges from each doctor during the last year, and the amounts not covered by a third party, such as insurance (including Medicare or Medicaid).

Previous physicians: List their full names, addresses, phone numbers, the type of practice, and the most common reasons they saw your child. Describe any important findings or treatment. Explain why you no longer choose to consult them.

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Dentist: List the name, address, and phone number of your child's dentist, as well as the frequency of exams. Indicate what special treatments or recommendations the dentist has made. Also list the best alternatives for dental care in case the current dentist is no longer available.

Nursing needs: Indicate your child's need for nursing care. List the reasons, procedures, nursing skill required, etc. Is this care usually provided at home, at a clinic, or in a doctor's office?

Mental health: If your child has visited a psychiatrist, psychologist, or mental health counselor, list the name of each professional, the frequency of visits, and the goals of the sessions. What types of therapy have been successful? What types have not worked?

Therapy: Does your son or daughter go to therapy (physical, speech, or occupational)? List the purpose of each type of therapy, as well as the name, address, and phone number of each therapist. What assistive devices have been helpful? Has an occupational therapist evaluated your home to assist you in making it more accessible for your child?

Diagnostic testing: List information about all diagnostic testing of your son or daughter in the past: the name of the individual and/or organization administering the test, address, phone number, testing dates, and summary of findings. How often do you recommend that diagnostic testing be done? Where?

Genetic testing: List the findings of all genetic testing of your child and relatives. Also list the name of the individual and/or organization performing the tests, address, phone number, and the testing dates.

Immunizations: List the type and dates of all immunizations.

Diseases: List all childhood diseases and the date of their occurrence. List any other infectious diseases your child has had in the past. List any infectious diseases your child currently has. Has your child been diagnosed as a carrier for any disease?

Allergies: List all allergies and current treatments. Describe past treatments and their effectiveness.

Other problems: Describe any special problems your child has, such as bad reactions to the sun or staph infections if he or she becomes too warm.

Procedures: Describe any helpful hygiene procedures such as cleaning wax out of ears periodically, trimming toenails, or cleaning teeth. Are these procedures currently done at home or by a doctor or other professional? What do you recommend for the future?

Operations: List all operations and the dates and places of their occurrence.

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Hospitalization: List any other periods of hospitalization your child has had. List the people you recommend to monitor your child's voluntary or involuntary hospitalizations and to act as liaison with doctors.

Birth control: If your son or daughter uses any kind of birth control pill or device, list the type, dates used, and doctor prescribing it.

Devices: Does your son or daughter need any adaptive or prosthetic devices, such as glasses, braces, shoes, hearing aids, or artificial limbs?

Medication: List all prescription medication currently being taken, plus the dosage and purpose of each one. Describe your feelings about the medications. List any particular medications that have proved effective for particular problems that have occurred frequently in the past and the doctor prescribing the medicine. List medications that have not worked well in the past and the reasons. Include medications that have caused allergic reactions.

OTC: List any over-the-counter medications that have proved helpful, such as vitamins or dandruff shampoo. Describe the conditions helped by these medications and the frequency of use.

Monitoring: Indicate whether your child needs someone to monitor the taking of medications or to apply ointments, etc. If so, who currently does this? What special qualifications would this person need?

Procurement: Does your child need someone to procure medications?

Diet: If your child has a special diet of any kind, please describe it in detail and indicate the reasons for the diet. If there is no special diet, you might want to include tips about what works well for avoiding weight gain and for following the general guidelines of a balanced, healthy diet. You might also describe the foods your child likes best and where the recipes for these foods can be found.

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What Works Well for _____ (Your son or daughter's name?)

Housing

Present: Describe your son or daughter's current living situation and indicate its advantages and disadvantages.

Past: Describe past living situations. What worked? What didn't?

Future: Describe in detail any plans that have been made for your son or daughter's future living situation. Describe your idea of the best living arrangement for your child at various ages or stages. Prioritize your desires. For each age or stage, which of the following living arrangements would you prefer?

- A relative's home (Which relative?)
- Supported living in an apartment or house with _____ hours of supervision
- A group home with no more than _____ residents
- A state institution (Which one?)
- A private institution (Which one?)
- Foster care for a child
- Adult foster care
- Parent-owned housing with _____ hours of supervision
- Housing owned by your child with _____ hours of supervision, etc.

Size: Indicate the minimum and maximum sizes of any residential option that you consider suitable.

Adaptation: Does the residence need to be adapted with ramps, grab bars, or other assistive devices?

Community: List the types of places that would need to be conveniently reached from your child's home. Include favorite restaurants, shopping areas, recreation areas, libraries, museums, banks, etc.

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Daily Living Skills

IPP: Describe your child's current Individual Program Plan.

Current activities: Describe an average daily schedule. Also, describe activities usually done on "days off."

Monitoring: Discuss thoroughly whether your son or daughter needs someone to monitor or help with the following items:

- Self-care skills like personal hygiene or dressing.
- Domestic activities like housekeeping, cooking, shopping for clothes, doing laundry, or shopping for groceries and cleaning supplies.
- Transportation for daily commuting, recreational activities, and emergencies.
- Reinforcement of social and interpersonal activities with others to develop social skills.
- Other areas.

Caregivers' attitudes: Describe how you would like caregivers to treat matters like sanitation, social skills (including table manners, appearance, and relationships with the opposite sex). What values do you want caregivers to demonstrate?

Self-esteem: Describe how you best reinforce your son or daughter's self-esteem, discussing how you use praise and realistic goal setting.

Sleep habits: How much sleep does your son or daughter require? Does he or she have any special sleep habits or methods of waking up?

Personal finances: Indicate whether your son or daughter needs assistance with personal banking, bill payments, and budgeting. If so, how much help is needed?

Allowance: Indicate whether you recommend a personal allowance for your son or daughter. If so, how much? Also, list your recommendations about supervision of how the allowance is spent.

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Education

Schools: List the schools your child has attended at various ages and the level of education completed in each program. Include early intervention, day care, and transition programs.

Current programs: List the specific programs, schools, and teachers your son or daughter has now. Include addresses and phone numbers.

Academics: Estimate the grade level of your son or daughter's academic skills in reading, writing, math, etc. List any special abilities.

Emphasis: Describe the type of educational emphasis (such as academic, vocational, or community-based) on which your son or daughter currently concentrates. What educational emphasis do you think would be best for the future?

Integration: Describe the extent that your child has been in regular classes or schools during his or her education. What are your desires for the future? What kinds of undesirable conditions would alter those desires?

Day Program or Work

Present: Describe your son or daughter's current day program and/or job.

Past: Describe past experiences. What worked? What didn't? Why?

Future: Discuss future objectives. Prioritize your desires.

Assistance: Indicate to what extent, if any, your son or daughter needs assistance in searching for a job, in being trained, in becoming motivated, and in receiving support or supervision on the job.

Leisure and Recreation

Structured recreation: Describe your son or daughter's structured recreational activities. List favorite activities and the favorite people involved in each activity.

Unstructured activities: What are your child's favorite means of self-expression, interests, and skills (going to movies, listening to music, dancing, collecting baseball cards, painting, bowling, riding a bicycle, roller skating, etc.)? List the favorite people involved in each activity.

Vacations: Describe your son or daughter's favorite vacations. Who organizes them? How often do they occur, and when are they usually scheduled?

Fitness: If your son or daughter participates in a fitness program, please describe the type of program, as well as details about where and when it takes place and who oversees it.

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Religion

Faith: List the religion of your son or daughter, if any. Indicate any membership in a particular church or synagogue.

Clergy: List any ministers, priests, or rabbis familiar with your son or daughter. Include the names of the churches or synagogues involved and their addresses and phone numbers. Also indicate how often your child might like to be visited by these people.

Participation: Estimate how frequently your son or daughter would like to participate in services and other activities of the church or synagogue. Indicate how this might change over time. Also describe any major, valued events in the past.

Rights and Values

Please list the rights and values that should be accorded your son or daughter. Here are some examples of what you might list.

- To be free from harm, physical restraint, isolation, abuse, and excessive medication.
- To refuse behavior modification techniques that cause pain.
- To have age-appropriate clothing and appearance.
- To have staff, if any, demonstrate respect and caring and to refrain from using demeaning language.

Other

Give an overview of your child's life and your feelings and vision about the future. Describe anything else future caregivers and friends should know about your son or daughter.

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Finances, Benefits, and Services for _____
(Your son or daughter's name)

Assets: List the total assets your child has as of this date. Indicate how those assets are likely to change—if at all—in the future.

Cash income: List the various sources of income your son or daughter had last year. Include wages, government cash benefits, pension funds, trust income, and other income. This might include Social Security, Social Security Disability Insurance (SSDI), or Supplemental Security Income (SSI).

Services and benefits: List any other services or benefits your child receives. These might be services for children with physical impairments, developmental disability services, clinics sponsored by support groups, early periodic screening, diagnosis and treatment, employment assistance, food stamps, housing assistance, legal assistance, library services, maternal and child health services, Medicaid, Medicare, Project Head Start, special education, Title XX service programs, transportation assistance, or vocational rehabilitation services.

Gaps: Indicate whether any services or benefits are needed but are not being received by your son or daughter. Indicate whether plans exist to improve the current delivery of services or to obtain needed benefits.

Expenses: List all expenses paid directly by your child in various categories, such as housing, education, health care, recreation, vocational training, and personal spending. List all expenses paid directly by parents, guardians, or trustees in various categories. List estimates of all expenses paid by third parties, such as insurance companies paying doctors directly or Medicaid paying for residential services.

Changes: Indicate how your child's financial picture would change if one or both parents died. Be sure to list any additional cash benefits to which your child definitely would be entitled. Also list any cash benefits for which your child might be eligible.

If you have further questions or would like to talk further about this Letter of Intent or anything else regarding your son or daughter, feel free to e-mail or call my office at:

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