



The Life Planning Approach

Don't make the mistake of waiting until after your will is prepared to write the all-important letter of intent.

By Christopher A. Poulos

A Letter of Intent is a non-legal document which is used to communicate and document your preferences to others. This can be used for many reasons, including explaining why a child has been disinherited or about the care of your minor child. For parents with a child with disabilities, it provides a guideline to others who someday may assist your son or daughter, whether a caregiver or the person who will make legal decisions for your child.

Most parents who have a child with special needs do not prepare wills because they feel uncomfortable with the traditional legal document approach. They choose to do nothing in preference to doing the wrong thing.

For the estimated 5 percent of the parents who do prepare wills, there is a typical scenario. An attorney advises them to disinherit their child and leave some resources to a testamentary special needs trust. The attorney may spend an hour counseling the parents and then have the secretary fill in the blanks of the boilerplate documents. For the most part, any resources will be managed by a trustee, who may or may not know the parents' desires. The tragedy is that the parents leave the attorney's office thinking they have done everything-that their estate plan is finished. By the time they reach their car, though, they may stare at the pieces of paper in their hands and wonder just how their child really will be taken care of in the future. They don't feel they have covered all the bases.

One of the greatest illusions in the estate planning field today is that the average family can guarantee a bright future for the person with special needs simply by preparing a will and a special needs trust. The truth is that a will and special needs trust rarely carry out the wishes of the family as intended unless the parents build a strong planning foundation by first developing a comprehensive and flexible life plan for their loved one with the disability.

The letter of intent is a personal letter drafted by you that will express your preferences for your child, including services, supports and other personal areas regarding your son or daughter. This letter differs from your Will because it does not convey legally binding directions, but rather is a personal letter to those people who will someday assist your child. As a parent, no

one knows your son or daughter better than you, including medical history, allergies, routines and habits, so this is a way for you to assist your child's next care giver to pick up where you left off.

The life planning approach calls upon the parents to take the following steps:

- Decide what they want for their 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 many prioritized options listed under each heading. The "child" may live another 50 to 60 years, and planning should try to cover the maximum life span.
- Put these hopes and desires in writing by using the non-legal document known as the letter of intent.
- Decide whether they need an advocate or a conservator to watch over their child.
- Decide who will handle the trust money to provide for their child.

All these decisions will affect the cost of the overall plan. The parents should look at a combination of resources to finance the plan, using government benefit programs like SSI and MediCal-if appropriate- as a foundation but bearing in mind that the government can change the rules and that benefits can go down the drain very quickly. The parents also should look at resources like savings, investments, insurance, the family estate and so on.

Ideally, the parents could now work with an estate-planning team, which might include an attorney experienced in developing special needs trusts, a fee-based financial planner, and a certified public accountant.

The parents would say, "This is what I want for my child. Help me implement it." The attorney, acting as the team leader, would counsel the parents and help mold their plan into sound legal documents that would work within the boundaries of social services, society and the legal system.

If families develop a sound life plan and use a special needs trust as a planning tool, it really doesn't matter if government rules change because the overall plan is still in place and the trust-if properly prepared- can serve other purposes so that the son or daughter with special needs continues to enjoy a comfortable and meaningful life style.

The Letter of Intent

The letter of intent will help the conservators, trustees and courts interpret your hopes and desires for your son or daughter. They will not have to depend solely on hard-to-understand legal documents, well meaning relatives and overworked government agencies.

The letter of intent is not a formal "legal" document, but the courts will rely on it for guidance in understanding your child and your wishes. The courts tend to favor the parents' wishes- unless their desires are illegal or morally questionable.

While teachers, doctors, caseworkers, and other professionals come and go, you remain a constant in the life of your son or daughter. By compiling information about your child and stating your desires for him or her, you will provide future caregivers the knowledge and insight to provide the best possible care. The wheel will not have to be reinvented. Caregivers will not have to waste precious time learning the most appropriate behavior or medical management techniques. You can tell them what works well.

Many parents of people with special needs find that they must overcome major emotional

hurdles in order to write this letter. It is usually the first time they have put in writing many of the concerns they have felt since their child was officially classified as disabled. It may be the first time family members have really discussed this important issue. However, parents must go through this very difficult step to guarantee a well planned future for their son or daughter.

You sign and date this letter just like any other. However, unlike the traditional letter, this one is never-ending. Unless you are on your deathbed, you may still have a lot of time to spend with your son or daughter. Each year you take out the letter. You may want to add to your letter of intent or revise it. Then you sign and date the new version.

Usually, additions or revisions to the letter can be made on a specific day each year, such as your child's birthday. Occasionally, there will be a significant change like a new residential placement or a bad reaction to a new type of medication that would require an immediate addition. Age and changes in circumstances may alter what is needed in the letter.

Incidentally, the letter of intent is not an essay for school. Don't worry about perfect grammar, spelling or the number of words. Your major concern is to make sure that your child will have a happy and meaningful life. Just make sure anyone who reads it in the future can understand exactly what you meant.

The letter can be addressed to "To Whom It May Concern." The letter can be typed or handwritten.

The letter should cover the key areas in your child's life. Describe what has happened thus far and express your desires for the future.



Writing your Letter of Intent

What do future caregivers need to know to provide the best possible care for your son or daughter?

All parents hope that even after their deaths, their children with special needs will continue to be as happy, healthy, productive and independent as possible- without undue risk. Though it is not a “legal” document, a letter of intent written by parents will be invaluable to future caregivers, conservators, and trustees. Also, a letter of intent can be a solid foundation for estate planning.

To write a letter of intent, just follow this guide, which covers vital statistics, your child’s financial picture, details about what works well for your child, suggestions about what changes might be needed for the future, and a list of the locations of all pertinent documents and records. The letter of intent documents your child’s life plan. When developing your child’s life plan, consult with your child, other family members, and professionals who know your child.

Because you probably won’t want to include your income and assets in your letter of intent, compile those figures separately.

Altogether, you should have most of the facts and figures needed for any comprehensive estate planning you need to do. In any event, this letter of intent will live on after your death to impart much of your knowledge of your son or daughter to future caregivers.

It is possible you will want to add some categories not listed in this guide. Make any adjustments necessary to fit the individual needs of your son or daughter. If both parents are living, one of you may want to do the actual writing of the letter of intent, while both of you may wish to sign it.

Whenever it seems advisable to update your letter of intent, you probably won’t need to redo the whole thing-just the pages where the changes have occurred.

***Note:** There will not be room for you to put your answers on this form. Please use these guidelines to write your letter of intent on separate sheets of paper. Be sure to include enough information. For instance, if you write down a Social Security number, be sure to include the words Social Security Number so that someone reading the document after your death doesn’t have to guess what those numbers represent. Also, using category headings similar to those in the guide may make it easier for anyone to find particular bits of information.*

LETTER OF INTENT

Written by: _____ Date: _____

(Relationship to the person with special needs)

To Whom It May Concern:

Information About (Your son or daughter's name)

GENERAL INFORMATION

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

Numbers: List the 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.

Marital Status: List the marital status of your son or daughter with special needs. 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, including how often they see them, what they like to do together and where they like to go.

Conservators: Indicate whether your child has been declared incompetent and whether any conservators have been appointed. List the name, address and phone number of each conservator and indicate whether that person is a conservator of the person or conservator of the estate, general or limited.

If successor conservators have been chosen, list their full names, addresses and phone numbers.

Trustee: Indicate whether you have set up a trust for your child. Indicate the full name of the trust (be sure to include the date it was signed, the tax identification number of the trust and list the full names, addresses and phone numbers of all the trustee's.

Representative Payee: Indicate whether your son or daughter has or needs a representative payee to manage public entitlements.

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.

Otherwise, 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?

MEDICAL HISTORY AND CARE

Diagnosis: 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, mental retardation, neurological disorder, physical disabilities, psychiatric disorder or an undetermined problem.

Seizures: Indicate the seizure history of your son or daughter: no seizures, no seizure in the past two years; seizures under control; seizures in the past two years, but not in the past year; or seizures currently.

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

Vision: Indicate the status of your son or daughter'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 son or daughter'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.

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 coverage for your son or daughter. What is included in this coverage now? Indicate how this would change upon the death of either parent.

Regular Physicians: List your child's regular physicians, including specialists. Include their full names, type of practice, address, phone numbers, the usual number of times your child visited them last year, the total charges from each doctor during the last year and the amounts not covered by third party.

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 treatments.

Dentist: List the name, address, 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.

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.

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 administering the test, 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 the occurrence. List any other infectious diseases your child has had in the past. List any infectious diseases your child currently has. Had 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 getting staph infections if he/she gets too hot.

Procedures: Describe any helpful hygiene procedures such as cleaning wax out of the ears every few months or trimming toenails. 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 (including sterilization) and the dates and places of their occurrence.

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 for him or her?

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 tell where the recipes can be found

for favorite dishes.

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 current 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 all those still living, list their addresses and phone numbers, as well as something about them.

Information About (Mother'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 current 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 all those still living, list their addresses and phone numbers, as well as something about them.

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. 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 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?

Favorites: List the favorite possessions that your son or daughter definitely would want to have in any living arrangement.

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.

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.

Caregiver's 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.

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*) that your son or daughter currently concentrates on. 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 further objectives.

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, 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.

RELIGION

Faith: List which religion your son or daughter belongs to, if any. Indicate any particular denomination or church your child is a member of.

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 bid 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.

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 of benefits your child receives. These might be services for children with physical impairments; developmental disability services; early periodic screening, diagnosis and treatment; employment assistance; food stamps; housing assistance; legal assistance; library services; maternal and child health services; MediCal; Medicare; Project Head Start; special education; Title XX service programs; transportation assistance; 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, conservators or trustees in various categories.

List estimates of all expenses paid by third parties, such as insurance companies paying doctors directly or MediCal 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 your child *definitely* would be entitled to. Also list any additional cash benefits your child *might* be eligible for.

The Paper Trail

Will: Describe the location of any will for your son or daughter and provide the names, addresses and phone numbers of the lawyers involved and of the executors.

Safe-Deposit Box: List any safe-deposits boxes owned by your son or daughter, the address of the depository, the contents and the name of any person who has power of attorney to enter the box.

Life Insurance: Describe any relevant life insurance-group of individual-on your son or daughter. List the face value, the insurance company, the policy number, the beneficiaries and where the policy is kept.

Burial Papers: List the location of the documents of burial for your son or daughter (deed,

PARENT'S FINANCIAL PICTURE

Use this guide to get an accurate view of your finances today. This will help you and legal or financial professionals determine if you need to make some different financial arrangements to take care of the future.

You can compile these figures for each parent separately or you can combine them- whichever is most appropriate for your individual situation.

Do not include the income and assets of your son or daughter with special needs.

ASSETS

Cash reserve assets:

- Checking accounts
- Savings accounts
- Money market funds
- Certificates of deposit
- Other cash reserve assets

Total: \$

Equity assets:

- Real estate owned
- Real estate partnerships
- Stocks
- Mutual Funds
- Other partnerships
- Variable annuities
- Business interests
- Cash value of life insurance
- Other equity assets

Total: \$

Total Assets:

Add cash reserve assets and equity assets.

Total: \$

MONTHLY INCOME

- Wages and salary
- Dividends from stocks
- Interest on savings, CDs, bonds
- Capital gains
- Pensions
- Social Security (specify type)
- Other

Monthly Income \$

MONTHLY EXPENSES

Mortgage payment or rent	Oil
Payments on other mortgages	Water
Automobile Loans	Telephone
Personal Loans	Trash collection
Charge accounts	Local government services
Income taxes	Household maintenance
Social Security	Gas/Transportation costs
Real estate taxes	Car maintenance
Life insurance	Furniture
Homeowners insurance	Education expenses
Automobile insurance	Contributions
Health insurance	Club dues/memberships
Other medical expenses	Entertainment
Food	Vacations
Clothing	Savings and investments
Electricity	Additional expenses for child
Gas	Other

Monthly Expenses \$

LIABILITIES

Home mortgage
Other mortgages
Bank loans
Auto loans
Charge accounts
Other debts

Total Liabilities \$

NET WORTH

Subtract your total liabilities from your total assets. This is your *net worth*.

Net Worth \$

MONTHLY DISCRETIONARY INCOME

If the total monthly income is the larger figure, subtract total monthly expenses from it. That gives you the *monthly discretionary income*. You might want to use some of this to build your estate.

Monthly Discretionary Income \$

(If the monthly expenses are larger than the monthly income, there is no *monthly discretionary income*.)