

# Letter of Intent for our Loved One with Special Needs



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# Creating Your Letter of Intent

PHOTO

## Creating Your Letter of Intent

The Letter of Intent is a letter of love to your child with special needs and those who will be entrusted with his or her care after you are unable to do so. It is a personal letter to those who will have the responsibility of making important personal decisions in providing the best possible care for your child.

The goal of this document is to memorialize your knowledge of your child's needs to help guide future caregivers, guardians, trustees and courts in understanding your hopes and dreams for your child.

It's easy to put off thinking about the long term. But, your child needs care and you may not always be there to provide it. By helping to plan your child's future, you can gain peace of mind that your child will be cared for in the years to come.

Collecting and documenting this information can seem a formidable task. The key is to start. You do not have to complete it all in one sitting. Develop the document over time and revisit regularly to keep it up to date. (Many people find it helpful to begin by keeping a journal for several weeks and recording notes and thoughts as they arise.) And, make your child part of the process so his or her wishes and preferences are respected and detailed.

In addition to developing the Letter of Intent, consider appointing a legal guardian for any child who is not expected to be able to manage personal financial or medical decisions without assistance. A special needs attorney can provide a framework for comprehensive planning and draft other important documents such as powers of attorney, a Special Needs Trust and health care proxies. The attorney can also explain how to allocate funds for the care of your child without jeopardizing eligibility for important means-tested government programs; and, can be a reliable resource for care managers, therapists and many other service providers within your community. You do not need to go through this process alone.

The professionals with whom you work can help you learn and understand the kinds of assistance that may be available, such as: Medicaid, Medicare, the State Children's Health Insurance Program or the Children with Special Health Care Needs provision of the Social Security Act.

With healthcare advances, individuals with disabilities are increasingly outliving their parents so, starting soon is very important, particularly as your child approaches his or her 18<sup>th</sup> birthday, since, in most states, that's the age of adulthood and you can lose access to your child's health, education, legal and financial records unless you take action, such as being appointed as legal guardian for your child.

Always keep a current copy of your Letter of Intent with your other estate planning documents to help ensure it will be found when needed.

## Points to Consider

- Where possible, you should avoid trying to develop a Letter of Intent alone. Involve family members, trusted friends, professional staff -- and, your child -- in creating the document. Your child will have a chance to think about his or her life and the kinds of things that are important to him or her. The letter should reflect his or her unique preferences and needs in every aspect of life.
- The letter should reflect your expectations for your child. Write the letter in non-technical terms. Be clear and detailed with your information; but, not too rigid. Understand that circumstances will change over time, so allow some flexibility to those who will be tasked with implementing your stated expectations. The information you provide should provide a framework that allows caregivers to provide the very best care – now and in the future.
- Although a Letter of Intent is not legally binding, its contents should not contradict any of your estate planning documents; especially, where you have a Special Needs Trust. An attorney specializing in special needs planning can help ensure the Letter of Intent is consistent with your trust and other legal documents and does not jeopardize eligibility for government assistance.
- Remember, the Letter of Intent is a dynamic document you will want to review, update and add to regularly, in order to make sure it always reflects your expectations and preferences for your child. This guide is intended as a framework for developing your Letter of Intent, with forms and suggestions on what to include; however, you should feel free to modify this document to fit your specific needs and the information you choose to provide on your special needs child.

This guide is divided into two sections: Data and Contacts, structured in a fact-gathering format; followed by a Narratives section where you can clearly lay out your feelings and expectations in as much detail as desired for the benefit of future caregivers and your child.

Some families like to add audio or video recordings to their narratives. If you wish to use recordings, consider adding selected recordings of you and your child for a personal touch to the information being passed on to caregivers and family. Make your recordings a supplement to the narratives rather than a replacement for them as recordings can make future edits and updates difficult.

## Data and Contacts

### *Loved One with Special Needs History and Data*

**Full Name:** \_\_\_\_\_ SS#: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Place of Birth: \_\_\_\_\_

Ancestry: \_\_\_\_\_ Religion: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Employer: \_\_\_\_\_ Phone: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

Diagnosis in Layman's Terms: \_\_\_\_\_

\_\_\_\_\_

Height: \_\_\_\_\_ Weight: \_\_\_\_\_

Shirt size: \_\_\_\_\_ Pant size: \_\_\_\_\_ Shoe size: \_\_\_\_\_

Dress size: \_\_\_\_\_ Suit size: \_\_\_\_\_ Waist size: \_\_\_\_\_

Needs Assistance:  Bathing  Cooking  Dressing  Eating  Finances  Toileting  Traveling

(Provide further details in the NARRATIVES that follow)

NOTES:

# Data and Contacts

## *Parent Information*

**Father's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Ancestry: \_\_\_\_\_ Religion: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Employer: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

Significant Medical History: \_\_\_\_\_

Who should be contacted in the event of your incapacity or death?

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Mother's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Ancestry: \_\_\_\_\_ Religion: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Employer: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

Significant Medical History: \_\_\_\_\_

Who should be contacted in the event of your incapacity or death?

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

(Add additional pages as needed)

## Data and Contacts

### *Sibling Information*

**Sibling's Full Name:** \_\_\_\_\_  Emergency contact

Date of Birth: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Sibling's Full Name:** \_\_\_\_\_  Emergency contact

Date of Birth: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Sibling's Full Name:** \_\_\_\_\_  Emergency contact

Date of Birth: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Sibling's Full Name:** \_\_\_\_\_  Emergency contact

Date of Birth: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Marital Status:  Married  Single  Divorced  Domestic Partner  Spouse/Partner Deceased

Spouse's/Partner's Name: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional pages as needed)

**Data and Contacts**  
*Family and Friends Information*  
(other than parents and siblings)

∠ **Family** ∠ **Friend Full Name:** \_\_\_\_\_  Minor or  Adult

Relationship to your Dependent: \_\_\_\_\_  **Emergency contact**

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

∠ **Family** ∠ **Friend Full Name:** \_\_\_\_\_  Minor or  Adult

Relationship to your Dependent: \_\_\_\_\_  **Emergency contact**

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

∠ **Family** ∠ **Friend Full Name:** \_\_\_\_\_  Minor or  Adult

Relationship to your Dependent: \_\_\_\_\_  **Emergency contact**

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

∠ **Family** ∠ **Friend Full Name:** \_\_\_\_\_  Minor or  Adult

Relationship to your Dependent: \_\_\_\_\_  **Emergency contact**

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional pages as needed)

**Data and Contacts**  
*Caregivers Information*  
(other than parents and siblings)

**Caregiver's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Employer / Agency: \_\_\_\_\_

Contact / Supervisor: \_\_\_\_\_ Phone: \_\_\_\_\_

**Caregiver's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Employer / Agency: \_\_\_\_\_

Contact / Supervisor: \_\_\_\_\_ Phone: \_\_\_\_\_

**Caregiver's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Employer / Agency: \_\_\_\_\_

Contact / Supervisor: \_\_\_\_\_ Phone: \_\_\_\_\_

**Caregiver's Full Name:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Employer / Agency: \_\_\_\_\_

Contact / Supervisor: \_\_\_\_\_ Phone: \_\_\_\_\_

(Add additional pages as needed)

**Data and Contacts**  
*Medical/Professional Staff Information*  
*(Physicians, Nurses, Therapists)*

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

(Add additional pages as needed)

## Data and Contacts

### *Medical/Professional Staff Information (Cont'd)* *(Physicians, Nurses, Therapists)*

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

**Full name:** \_\_\_\_\_  Emergency contact

Professional designations: \_\_\_\_\_

Specialty: \_\_\_\_\_

Relationship (or role) to dependent: \_\_\_\_\_

Preferred phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

Instructions and Comments: \_\_\_\_\_

\_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

## *Prescriptions and Medications*

**Medication Name:** \_\_\_\_\_ / Currently taking

Dosage: \_\_\_\_\_ Date Prescribed: \_\_\_\_\_

Reason: \_\_\_\_\_

Prescribed by: \_\_\_\_\_

Instructions: \_\_\_\_\_

**Medication Name:** \_\_\_\_\_ / Currently taking

Dosage: \_\_\_\_\_ Date Prescribed: \_\_\_\_\_

Reason: \_\_\_\_\_

Prescribed by: \_\_\_\_\_

Instructions: \_\_\_\_\_

**Medication Name:** \_\_\_\_\_ / Currently taking

Dosage: \_\_\_\_\_ Date Prescribed: \_\_\_\_\_

Reason: \_\_\_\_\_

Prescribed by: \_\_\_\_\_

Instructions: \_\_\_\_\_

**Medication Name:** \_\_\_\_\_ / Currently taking

Dosage: \_\_\_\_\_ Date Prescribed: \_\_\_\_\_

Reason: \_\_\_\_\_

Prescribed by: \_\_\_\_\_

Instructions: \_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

*Legal • Estate • Financial*

**Current Guardian:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Alternate Guardian:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Trustee:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Executor:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Power of Attorney:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Health Care Proxy:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Financial Advisor:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional pages as needed)

## Data and Contacts

### *Legal and Other Documents*

**Special Needs Attorney:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Attorney:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Attorney:** \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional listings as needed)

Check the documents you have established with your attorney:

Document	Date*	Location of Document
<input type="checkbox"/> Will		
<input type="checkbox"/> Living Will		
<input type="checkbox"/> Estate Planning Trust		
<input type="checkbox"/> Durable Powers of Attorney		
<input type="checkbox"/> Health Care Proxies		
<input type="checkbox"/> Guardianship		
<input type="checkbox"/> Special Needs Trust		
<input type="checkbox"/> Letter of Intent		
<input type="checkbox"/> Other		
<input type="checkbox"/> Other		

\*Enter the date the document was created; *OR*, the date it was last updated. Many of these documents -- such as the Letter of Intent -- need to be updated regularly to make certain they remain current.

# Data and Contacts

## *Powers of Attorney*

**Full Name of Power Holder:** \_\_\_\_\_

Describe the Power of Attorney: \_\_\_\_\_:  Durable

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Full Name of Power Holder:** \_\_\_\_\_

Describe the Power of Attorney: \_\_\_\_\_:  Durable

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Full Name of Power Holder:** \_\_\_\_\_

Describe the Power of Attorney: \_\_\_\_\_:  Durable

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

## *Powers of Attorney for Health Care*

**Full Name of Power Holder:** \_\_\_\_\_

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Full Name of Power Holder:** \_\_\_\_\_

Describe the Power of Attorney: \_\_\_\_\_:  Durable

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Full Name of Power Holder:** \_\_\_\_\_

Describe the Power of Attorney: \_\_\_\_\_:  Durable

Relationship to your Dependent: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Work Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

## *Insurance*

**Insurance Advisor:** \_\_\_\_\_

Lines of Insurance: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Insurance Advisor:** \_\_\_\_\_

Lines of Insurance: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

**Insurance Advisor:** \_\_\_\_\_

Lines of Insurance: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Full Address: \_\_\_\_\_

(Add additional listings as needed)

<b>Line of Insurance</b>	<b>Advisor</b>	<b>Phone</b>
Primary Medical		
Secondary Medical		
Life		
Dental		
Vision		
Other:		
Other:		

# Data and Contacts

## *Government Benefits*

**Name of Government Benefit:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Government Benefit:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Government Benefit:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Government Benefit:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

## *Community Services*

**Name of Community Service:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Community Service:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Community Service:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

**Name of Community Service:** \_\_\_\_\_

Description: \_\_\_\_\_

Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Case #: \_\_\_\_\_ Email: \_\_\_\_\_

Comments / Frequency / Amount: \_\_\_\_\_

(Add additional pages as needed)

# Data and Contacts

## *School and Education*

**School Name:** \_\_\_\_\_ Grade: \_\_\_\_\_

Full Address: \_\_\_\_\_

Contact Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Extra-Curricular Activities: \_\_\_\_\_

\_\_\_\_\_

Instructions: \_\_\_\_\_

\_\_\_\_\_

**School Name:** \_\_\_\_\_ Grade: \_\_\_\_\_

Full Address: \_\_\_\_\_

Contact Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Extra-Curricular Activities: \_\_\_\_\_

\_\_\_\_\_

Instructions: \_\_\_\_\_

\_\_\_\_\_

# Data and Contacts

## *Religion and Worship*

**Religious Preference:** \_\_\_\_\_

House of Worship: \_\_\_\_\_

Full Address: \_\_\_\_\_

Religious Leader's Title and Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Contact Name: \_\_\_\_\_ Role: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Contact Name: \_\_\_\_\_ Role: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Activities and Worship Details: \_\_\_\_\_

\_\_\_\_\_

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Narratives

**Family History:** Where and when you were born, raised, and married, including anecdotes about your own siblings, grandparents, and other relatives or special friends. A description of your child's birth and his or her connections to specific family members or friends will complement your account of favorite memories and feelings about your child.

NARRATIVE:

\*The topics and descriptions for the Narratives were "Reprinted with permission of the Special Needs Alliance – [www.specialneedsalliance.org](http://www.specialneedsalliance.org)." They were written by Special Needs Alliance member Amy C. O'Hara and her co-author, Sheryl Frishman. Amy and Sheryl are attorneys with the New York law firm Kittman Krooks LLP, specializing in special needs planning.

# Narratives

**General Overview:** A brief summary of your child's life to date and your general thoughts and hopes about the future for your child.

NARRATIVE:

# Narratives

**Daily Schedule and Personal Care:** Because levels of functionality vary for each child and future caregivers may fail to recognize this fact, it is important to list your child's daily routines, favorite activities, and events or tasks he or she loves or hates. Because a child's ability to contribute to even the most mundane aspects of family life builds self-esteem, it is important that the letter mention whether your child can help with tasks like doing the dishes or raking leaves. Alternatively, if your child loves organizing things, but folding clothes frustrates him or her, make sure future caregivers have this information.

To provide framework for this over-arching topic, start by checking activities with which your child needs assistance, then use the narrative to provide further details as needed.

My child needs assistance with the following *activities of daily living*:

- Bathing / showering and personal hygiene
- Cooking
- Dressing
- Eating
- Finances and handling money
- Going out and traveling (can he or she travel alone?)
- Reading, writing, communicating and understanding what others say
- Ride public transportation
- Toileting
- Other:
- Other:

NARRATIVE:

## Narratives

**Food:** Describe your child's diet, including his or her favorite foods and any specific manner in which the food should be prepared or served. Be certain that the letter also includes a list of foods to which your child is allergic, simply does not like or otherwise may react adversely due to medication.

NARRATIVE:

# Narratives

**Medical History and Care:** Describe in detail your child's disability, medical history and allergies (food, drug, environmental, pets), as well as current doctors, therapists and hospitals. Detail the frequency of your child's medical and therapy appointments and the purposes and goals of these sessions. List current medications, including how they are administered and for what purpose, and be careful to describe all medications that have not worked for your child in the past.

Also, include where medications are kept and those who have been provided Health Care Proxies.

NARRATIVE:

## Narratives

**Education:** Detail your child's educational experiences and describe your desire for your child's future education, including regular and special classes, specific schools, related services, mainstreaming, extracurricular activities and recreation. Discuss your wishes regarding the types of educational emphasis, i.e., vocational, academic or total communication, and name any specific programs, teachers, or related service providers that you prefer to be part of your child's overall life plan. Describe relevant school history; and current support personnel and activities.

NARRATIVE:

## Narratives

**Benefits Received:** List the types of governmental benefits your child receives, including Medicaid, Medicare, SSI/SSDI, Supplemental Nutrition Assistance Program (food stamps), and housing assistance. Detail the agencies' contact information, identification numbers for your child's case(s), the recertification process for each benefit, including important dates and other reporting requirements.

NARRATIVE:

## Narratives

**Employment:** Describe the types of work and work environments your child may enjoy; i.e., open employment with supervision, a sheltered workshop or an activity center. List any companies of which you are aware that provide employment in the community and may be of specific interest to your child.

NARRATIVE:

## Narratives

**Residential Environment and Living Arrangements:** Describe your child's living arrangements with family, friends or other organizations. If your child will be unable to continue living with these individuals after you stop being the primary contact for his or her care, describe what you consider to be the best alternative arrangements. For instance, explain whether you prefer that your child live in a group home or institution located in the same community, the preferred size and location of the institution, or that your child have a single room or roommate.

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**Social Environment:** Mention the types of social activities your child enjoys, i.e., sports, dances, or movies. Indicate whether your child should be given spending money and, if so, how he or she has spent money in the past. The letter of intent also should note whether your child takes and/or enjoys taking vacations and, if so, whether he or she has a favorite travelling companion.

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**Religious Environment and Spirituality:** Specify your child's religion and any local place of worship your family attends. List all local clergy that may be familiar with your child and your family. Describe your child's religious education and indicate whether this is of interest to your child.

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**Behavior Management:** Describe any current behavior management program that is having a positive impact on your child and discuss any other behavior management programs that were unsuccessful in the past.

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**Your Child's Preferences:** Your child should have an active role in the overall development of the Letter of Intent; however, he or she can really take the lead in this narrative about his or her unique preferences. This may even be a section where including some recordings might be fun and helpful.

Here is some information and questions that may be useful in getting started when working on this narrative with your child:

Who are the people close to you (family, school, neighbors and friends)?

Who are the people you like to be with most?

What are some great things about you (things you are good at and proud of)?

What are some things you want to accomplish (in life, at school and work)?

What are some fun things you like to do (at home, vacation, school and work)?

What are some things you enjoy doing during the week? On the weekends?

What are some things you do not like to do?

Describe some items that are important to you (electronic devices, pets, bike)?

What kind of music, movies and food do you like? Do you not like?

Do you collect things? Have a hobby?

What are your shared hopes and dreams for the future?

This is clearly only a start to the many discussions and preferences you can include in your Letter of Intent. And, as you interact with your child, other discussions, topics and conversations will provide further insight into the information and directions that should be included in this narrative.

**NARRATIVE:**

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**Final Arrangements:** List your desires for your child's final arrangements, including whether you have planned for a funeral, cremation or burial, and any cemetery, monument, religious service or specific clergy to officiate the proceeding.

NARRATIVE:

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**Other Information:** Include any other information that you believe will provide the best possible guidance to the person who assumes responsibility for caring for your child.

NARRATIVE: