

# **Letter of Intent for our Loved One with Special Needs**

**PHOTO**

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## 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 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 may need assistance managing personal financial or medical decisions. 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 legal and estate planning documents and provide a copy to your attorney to help ensure it is readily available and addressed when needed.

Once you sign and date the Letter of Intent, review it annually and update it as needed to keep it current. And be sure to review and discuss the document with your child's designated caregivers on a regular basis.

- 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 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 child with special needs. Add pages where needed; cut-and-paste when helpful; and, add additional topics to round-out the information you feel the caregivers will need to provide the care, lifestyle and experiences you desire for your 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 add audio or video recordings to their narratives. Consider adding selected recordings of you and your child as a personal touch to the information 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)

Line of Insurance	Advisor	Phone
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

## *Schooling 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

**General Overview:** Start framing the “big picture” with a summary of your child’s life to date and your general thoughts and hopes about the future for your child. As you do this, relate his or her growing-up to events and people in your family’s background. Provide details about you and your family. Where were you born and raised? Provide some history on parents, grandparents, siblings, close relatives and friends. Facts are important; but, so are interesting stories and insights to help provide a basis for understanding your child’s background and the atmosphere or environment in which he or she has been raised and cared for.

NARRATIVE:

# Narratives

**Daily Schedule / Personal Care:** Your child's daily schedule may be at the core of what caregivers need to know and understand to provide the best care and environment for your child. For many children, routine and predictability are important and likely reassuring. Describe your child's routines and try to break them into natural segments. An example of this may include: his or her waking and morning routine; preparing for and attending school routine; afternoon and after-school activities; evening, dinner, homework and bedtime routines.

Which tasks and activities does your child enjoy; which does he or she avoid? Think of this as a roadmap for caregivers that provides clear directions as to what your child finds enjoyable and fulfilling. Since building self-esteem is important to developing confidence, independence and growth, mention tasks or chores your child can help with as well as those he or she likes.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Family and Friends](#)

[Click here for Caregivers](#)

[Click here for Prescriptions and Medications](#)

This is a big topic with lots of parts. To break it down a bit, start by considering those activities with which your child needs assistance and then use the Narrative below to provide any helpful 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

**Nutrition:** Describe your child's diet. Are their particular routines or "rules" related to the preparation, serving or consumption of food, snacks and meals? What are your child's favorite foods; what does he or she refuse to eat? Specify any food allergies that would be important for caregivers to know about; or, food that causes adverse reactions to medications? Any special preparation instructions? Is your child capable of preparing meals and eating on his or her own; or does he or she need assistance or supervision?

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Family and Friends](#)

[Click here for Caregivers](#)

[Click here for Prescriptions and Medications](#)

NARRATIVE:

# Narratives

**Medical History and Care:** Precise instructions and details about your child's medical care and disability are critical. To give this Narrative context, begin by describing your child's disability, in layman's terms, so it will be clear for caregivers to understand and follow. What is your child's disability and how does it manifest? Provide a medical history of your child's diagnoses, care and progress. Detail medical and therapy appointments, including the frequency, purpose and goals of these sessions.

The Data and Contacts references below will help collect information on your child's physicians, therapists, medications, hospitals and medical facilities. Include medications that were discontinued, and why; where medications are kept; and, those who have been provided Health Care Proxies.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Medical/Professional Staff](#)

[Click here for Prescriptions and Medications](#)

[Click here for Powers of Attorney for Health Care](#)

NARRATIVE:



# Narratives

**Schooling and Education:** Describe your child's educational history, including regular and special classes, and what you foresee as his or her future and long-term educational potential and goals. Do you have specific schools in mind? What about extracurricular and recreational activities that you see enriching your child's life? Do you have an educational emphasis you would want caregivers to consider? Do you know about any special programs, teachers or service providers you would want involved in these decisions and your child's education and mainstreaming?

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Schooling and Education](#)

[Click here for Siblings](#)

NARRATIVE:

# Narratives

**Benefits Received and Community Resources:** List all government benefits your child receives or may be eligible to receive. This might include Medicare, Medicaid, SSI/SSDI, and such. Don't overlook resources offered within your community. Your special needs attorney or care manager should be able to help with this Narrative.

The Data and Contacts references below will help you collect and record this information for the caregivers.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Government Benefits](#)

[Click here for Community Services](#)

NARRATIVE:

## Narratives

**Employment:** If your child is currently employed, explain his or her responsibilities and the type of work he or she does, and for how long. Does your child enjoy his or her job? If your child is not currently working – or, may want to change jobs in the future -- what type of work do you feel your child would enjoy and be able to undertake? Consider the level of functionality of your child when developing this Narrative. Describe any supervision your child may require on the job. What type of work would he or she enjoy and do well with? Could he or she work outside, unsupervised; or, is a controlled environment -- such as a sheltered workshop or activity center – more suitable? Are there any companies within your community that might be a good match and of specific interest for your child?

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Caregivers](#)

NARRATIVE:

# Narratives

**Residential Environment and Living Arrangements:** Detail your child's living arrangements. Does he or she live at home full time? Are there other occasional or routine living arrangements with family, friends or other organizations? Would family, friends and organizations be residential options for your child once you are no longer the primary caregiver? If not, describe what you feel would be alternatives. Be specific about the arrangements you feel would be preferable. What size facility would suit your child best? Would your child feel more comfortable with single accommodations or a roommate? Provide some insight into how you would expect your child to adapt to a new living arrangement and what can be done to make the transition smooth and pleasant for your child.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

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[Click here for Family and Friends](#)

[Click here for Caregivers](#)

NARRATIVE:

# Narratives

**Social Environment:** What types of social activities does your child enjoy; what makes him or her happy? How much supervision does your child need in various social environments? Does he or she do well in large, loud crowds and venues, such as sporting events and concerts; or better with more intimate groups and close friends, such as arts and crafts, dances and movies? Does your child need close attention or supervision in social environments? Can he or she deal with money on his or her own? On what type of transportation does your child usually depend for getting about? If he or she drives, please provide background on any limitations or incidents that should be considered. What kinds of outings or vacations does your child enjoy; and with whom does he or she often travel? List the name and address of day programs, sports programs or other programs in which your child regularly participates.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Family and Friends](#)

[Click here for Caregivers](#)

NARRATIVE:

## Narratives

**Religious Environment and Spirituality:** Specify your child's religion and your family's primary place of worship. How engaged is your child with your place of worship and committed to religious teachings? Would he or she have an interest in continuing his or her religious education and maintaining his or her religious connections?

The Data and Contacts references below will help you collect and record information on the place of worship and clergy who may be familiar with your child and family.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Family and Friends](#)

[Click here for Religion and Worship](#)

NARRATIVE:

# Narratives

**Behavior Management:** Describe any behavior management programs in which your loved one is currently participating, and your observations. Are you happy with the program? What are your expectations; are you getting positive results? Discuss any programs that might have been unsuccessful in the past and why.

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

[Click here for Caregivers](#)

[Click here for Medical/Professional Staff](#)

[Click here for Prescriptions and Medications](#)

NARRATIVE:

# Narratives

**Your Child's Preferences:** Help your child take an active role in developing this Letter of Intent. Use this narrative to provide details of his or her unique preferences. You might even choose to include some video and/or audio recordings to make it more fun, helpful and personal.

The following information and questions can help you get started on filling in 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?

Another wonderful aspect of this narrative is the many discussions and preferences you will uncover with your child in developing this Letter of Intent. As you interact with each other, you'll likely uncover other discussions, topics and conversations to address and include here and in the other Narratives.

NARRATIVE:



## Narratives

**Final Arrangements:** Discuss your desires for your child's final arrangements. Have plans been made for a funeral, burial or cremation? Have you spoken to clergy about arrangements, preferences and specific services? What is your child's expected longevity?

FOR CONTACTS AND INFORMATION, REFER TO THE PREVIOUS [DATA AND CONTACTS SHEETS](#) OR:

[Click here for Siblings](#)

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[Click here for Legal, Estate and Financial](#)

NARRATIVE:

# Narratives

**Other Information:** Remember, this Letter of Intent is a *guide* for you to include any information that communicates your desires and preferences to the caregivers who have assumed the responsibility of caring for your special child when you can no longer do so.

Create and modify this Guide as necessary to ensure it addresses your specific needs and desires, and those of your loved one.

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NARRATIVE: