



Writing a Letter of Intent for Special Needs

What is a Letter of Intent?

It is a document written by the primary caregivers (often parents) of an adult with intellectual/developmental disabilities (I/DD) so that others can step in and provide care if necessary. For example, it can be used if the primary caregivers are unavailable due to a short or extended absence or after their death. The Letter of Intent provides vital practical information and instructions that can be shared with service providers, Regional Center, and others in close contact with your adult child. It can also pass along values and personal desires. Ideally, the adult with special needs is involved in writing this letter, so that it represents them and helps shape their future. This letter should be updated (annually, as needed) to reflect changes to important information and the changing needs, desires, and interests of the adult with special needs.

The Letter of Intent is not a legal document, but it can serve as guidance to the courts and others in understanding the adult with I/DD, as well as the primary caregiver's wishes for this person. **The Letter of Intent should never take the place of a will, trust, or formal guardianship/conservatorship.** Instead, it addresses matters that are not generally covered in these formal legal documents.

Why is it important?

Many adults with I/DD can communicate their needs and desires on their own, but others may have limited or no ability to communicate. In addition, people who currently have communication skills may lose them in the future, for example, if they develop dementia.

The Letter of Intent is designed to help the person with special needs make transitions as easy as possible, especially the planned or unexpected absence of a caregiver can throw a person's life into an upheaval. Having important information available and documenting daily life routines helps both the person with special needs and the next caregiver.

What should be in the Letter of Intent?

- Name of the person with I/DD, along with diagnosis, birth date, home address, phone number, and current household member information.
- Name of the people who prepared the Letter of Intent.
- Detailed information, including contact information, on current (and past, if relevant) day programs and/or employment. Include future employment plans. List volunteer and training activities.
- Names and contact information of other involved family members and close friends.
- Information on the individual's daily schedule and routines.

- Names and contact information of primary doctor, dentist, medical specialist, Regional Center Service Coordinator and/or other social workers, clergy and attorney/accountant/insurance agent, if appropriate.
- If respite care is provided, please specify the number of hours and other pertinent information.
- Medical history with diagnoses, level of functioning, vision, hearing, speech and communication skills, mobility, blood type, nursing needs, mental health, therapies, immunizations, allergies, any major medical procedures, operations, hospitalizations, birth control, prescription and non-prescription medicines.
- Healthcare coverage information (Medicare/MediCal, private insurance, etc.).
- Names of Conservator(s)/Power of Attorney agents
- Food preferences/food restrictions.
- Residential preferences with names of agencies assisting, if possible.
- Educational history with names of schools, years attended and academic skills, along with any vocational training.
- Sources of income, such as SSI, if applicable.
- Daily living skills, habits and behavior in bathing, dressing, toileting, preparing meals, eating, laundry and cleaning as well as financial skills, sleep habits, and challenging behaviors and behavior management tools.
- Religious preference and if the person is a member of a church, synagogue or other establishment, with the name and address of the house of worship and clergy's name.
- A list of their social/recreational activities and how often they engage in those activities, along with any contact information/details for the recreational activities.
- A description of the families overarching values, such as their overall wishes for the individual with I/DD, in such areas as independence, romance, and community inclusion vs. separate special needs programs.

Often, much the information listed above can be found in your Regional Center's Individual Program Plan (IPP). Also, you may find it useful to attach the IPP, other pertinent documents, or additional information to the Letter of Intent.

Who Should Receive a Copy of the Letter of Intent?

Copies should be given to the Regional Center Service Coordinator, primary physician, siblings, key relatives and friends, attorney, and day program administrator.


Sample Letter of Intent and Letter of Intent Form

A sample Letter of Intent is attached to help you better understand the nature of this document. You can use it to help guide you in writing a Letter of Intent. You may instead choose to complete the attached Letter of Intent form. Seeking input from the person with I/DD is valuable and a questionnaire for them to complete is also attached.

Thanks-this form was adapted from and inspired by <http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm> and the Autism Speaks Resource Guide at AutismSpeaks.org.

Other resources for writing a Letter of Intent:

- 1) On-line form to fill out from the Special Needs Alliance:
<http://midmoelderlaw.com/forms/LetterofIntent.pdf>

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- 2) Footprints for the Future, a personal planning tool from the Arc of East Middlesex http://www.ndss.org/PageFiles/3022/footprints_for_the_future.pdf
 - 3) Top ten items to include in a Letter of Intent for Special Needs from the Friendship Circle of Michigan <http://www.friendshipcircle.org/blog/2013/04/03/the-top-10-items-to-have-in-your-letter-of-intent/>

Sample Letter of Intent

This sample gives you an idea of how a Letter of Intent can read. Your actual letter may contain more detail.

LETTER OF INTENT FOR LORI GARCIA

Note: This is an advisory letter intended to provide information about Lori that can be used by others in the event that we, Lori's caregivers, are not available due to absence, illness or death. This Letter provides vital practical information and instructions for those that will assume or assist in Lori's care. It will help you understand Lori's world, her needs, and desires. Lori has given input into this Letter. This Letter is not a legal document, like a Will, but instead it addresses more day-to-day matters.

A copy of this letter has been given to Lori's: primary doctor, Regional Center coordinator, siblings, family attorney, and certain friends and family members. The individual's names are listed at the end of this letter.


May 1, 2014

Re: Our daughter, Lori Garcia

Our daughter Lori is a vibrant young woman with autism. Lori will likely need assistance throughout her life so that she can reach her full potential. Below is key information to assist you in assisting Lori.

1. **Contact the following people if anything should happen to us:** *Name, phone number, e-mail address, and street or city/state of other children, involved extended family and close friends, case manager/coordinator, doctor, lawyer, clergy, school, etc.*
2. **Current situation and family life:** Lori is an eighteen-year-old (DOB 05/10/1995) with autism. She has two brothers James and Mathew. She lives with both parents and James. At home, she enjoys reading nature books, playing computer games, practicing guitar, and helping in the kitchen. She enjoys family outings such as hiking, visiting family and friends, and going to restaurants. In

- addition, she loves animals and spending time with the family cat and dog. She participates in a social skills group at the YMCA. She is generally happy, engages with close family friends and relatives, and is fully verbal, but sometimes shy with others. Despite this shyness she has shown an interest in boys and recently began socializing with one of them. Lori takes care of her personal hygiene needs, does her own laundry (with prompting and occasional help), keeps her room orderly, and enjoys preparing simple meals.
3. **Daily schedule and routine:** Monday through Friday, Lori attends school from 8:00 A.M. until 2:00 P.M. Her parents or brother drive her. On Tuesdays and Thursdays, Social Connections Today (a Regional Center vendored autism social skills group in Santa Clarita) picks Lori up from School and they engage in activities at the Canyons YMCA and once a month goes on an outing. While at the Y. Lori will also swim with the Special Olympics group. Lori eats dinner by 7:00 and is bed by 9:30. Lori is very adamant about her dinner and bedtime. On Saturdays, Lori volunteers at Nine Lives, a local cat rescue group and occasionally participates in a Special Olympics swim meet. She sometimes attends Grace Lutheran Church on Sundays.
 4. **Contact Information for Lori:** 5283 La Rosa Drive, Santa Clarita, CA. Home (661)xxx-xxxx and Lori's Cell (661)xxx-xxxx. Also list cell phone numbers for parents and siblings, other caregivers.
 5. **Education:** Lori is in a special education class at Oliver James Education Center. Her strengths are memory, music, and computers. Writing and expressing new concepts is challenging. In the future, she could attend (with support) a vocational school with opportunities such as animal care. We are considering American Victory Vocational School in Valencia and hope she can attend in another year.
 6. **Employment/Volunteering/Training:** Lori has an interest in animals and cooking and is skilled with computers and many common programs. She would probably enjoy working at an animal shelter, a pet store, or maybe in the food service industry. She might find work requiring computer expertise. Her current volunteer work with the cat rescue group involves computer work in addition to caring for the animals.
 7. **Future Residence:** Lori would like to someday share an apartment with a roommate. She will likely need a support worker to check in with her daily (or perhaps less frequently) to help with activities of daily living, banking, or general support. Lori can prepare simple meals for herself. Lori's name is on a long waiting list for the Supported Independent Living Apartment Program, offered through the Tri-City Community Support Center. Her Regional Center case manager (information below) is assisting Lori with placement. Alternatively, she could move in with Matthew, her oldest brother, who has a basement apartment in his home.
 8. **Medical Matters/Insurance:** Lori has no chronic medical conditions. She is seen for a yearly check up by Dr. Ken Miyata (*contact information*), who is familiar with Lori's strengths and challenges. In addition, she sees an eye doctor (*name and contact information*) and dentist (*name and contact information*) with special needs expertise. Lori takes an oral contraceptive. Lori is not allergic to any medications. However, in the past, she has experienced adverse side effects from the following medications, which should be avoided in the future: (*list drugs and adverse reactions*). Lori's healthcare insurance is (*list*).

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9. **Regional Center/Public Benefits:** Lori is a client of North Hills Regional Center. Her service coordinator, Vera Henley, can be reached at *(contact information)*. Lori does not receive any other public benefits at this time.
 10. **Behavior Management:** Lori prefers her own company or that of her family and close friends. She sometimes withdraws in new social situations and can become anxious when her expectations or routines change. She will sometimes rock, pinch herself, or get teary when she is anxious. This usually happens when she is not clear on what is happening or what her day holds for her. The best strategy is to provide her with a written schedule or calendar of what will be happening in the day and reinforcing that change may occur and reminding her how to deal with it. Lori has been seen by a behavior therapist whose contact information is *(contact info)*. They will consult on any future behavioral issues that may arise.
 11. **Social:** Lori participates in her social skills group and Special Olympics swimming at the Canyons YMCA. She takes occasional cooking classes offered at the YMCA and at local stores and restaurants. She enjoys interacting with others at the cat rescue group. She also greatly enjoys visiting our family and friends. She's recently shown an interest in dating and as she puts it, "growing up."
 12. **Religious/Spiritual Life:** Most Sundays, Lori attends services with us at Grace Lutheran. In addition, she occasionally attends the church's young adult's social programs.
 13. **Conservatorship, Trust, Will:** We are Lori's current conservators. Her oldest brother, Mathew Garcia, is willing to act as Lori's conservator in our absence. Additional information and trustee assignments are set forth in our wills and trust, which were last updated on *(insert date)* and are on file with *(attorney name, contact information)*.

Attached is Lori's last Regional Center IPP, which also covers some of the matters described above.

Signed by:

Daniel James Garcia - father

Myrna Lori Garcia – mother

A copy of this letter was given to:

Letter of Intent- Template

Note: This is an advisory letter intended to provide information about _____ (*Insert name of son/daughter with I/DD here and throughout the paragraph*) that can be used by others in the event that we, the caregivers, are not available due to absence, illness or death. This Letter provides vital practical information and instructions for those that will assume or assist in _____ care. It will help you understand _____ world, needs, and desires. _____ has given input into this Letter. This Letter is not a legal document, like a Will; instead it addresses more day to day matters.

A copy of this letter has been given to our son/daughter's: primary doctor, Regional Center coordinator, siblings, family attorney, and certain friends and family members. The individual's names are listed at the end of this letter.

Date: _____

Re: _____ (*Insert son/daughter's name*)

1. Contact the following people if anything should happen to me/us: (*List the name, phone number, e-mail address, address or city/state of other children, extended family and close friends, case manager/coordinator, doctor, lawyer, clergy, school, etc.*)

<i>Name</i>	<i>Relationship</i>	<i>Email</i>	<i>Phone</i>	<i>Address</i>

2. Current situation and family life: (*List your child's age, diagnosis, where he/she lives and with whom, what he/she enjoys doing at home, what activities he/she is involved in – both at home and outside of home, how verbal and social he/she is, etc. Please include anything you feel is important to your child's current home and family life.*)



3. Daily Schedule and routine: *(List your child's weekday and weekend schedule or routine, e.g.: Monday through Friday attends community work center for the I/DD from 8 A.M. until 2 PM; Tuesdays and Thursdays swims at Boys and Girls Club from 7-8 PM; Saturday 9-11 AM volunteers at animal shelter; Sunday 9:30-11 AM attends church service; etc.)*

4. Contact Information: *(List your child's street address and phone numbers as well as your contact your information.)*

5. Education: *(Describe if your child is currently in school or a day program, what support he/she receives, his/her strengths and challenges, what you see for his/her educational future?)*

6. Employment/Volunteering/Training: *(List current employment, including sheltered workshop and competitive employment. List volunteer and training activities. List any future employment you believe your child can engage in and any steps or training taken and contacts.)*

7. Future Residence: *(Where do you see your child living in the future? For example: independently or with support services in an apartment, group home, childhood home, with family member, etc.)*

8. Medical Matters/Insurance: *(List any medical conditions/challenges, allergies, prescription or other medicines taken, birth control, etc. List all doctors (with their specialty) who care for your child. List healthcare insurance, MediCal, etc.)*

9. Regional Center/Public Benefits/Income Source: *(List Regional Center contact information, if applicable. List any public benefits received, e.g., SSI or other income source.)*

10. Behavior Management: *(List your child's behavioral and personality traits that impact his/her life and interactions with others. List strategies that help, therapist or other specialist he/she has worked with, etc.)*

11. Social: *(List community programs like YMCA cooking classes, church groups, Special Olympics, etc. List close family ties.)*

12. Religious/Spiritual Life: *(List any church, temple or other religious/spiritual organization group your child may participate in and contact information. List other pertinent information.)*

13. Conservatorship, Trust, Will: *(List any conservatorship that may be in place with conservator names and document date. List any applicable wills or trusts, document dates, and attorney contact information.)*

14. Other Relevant Information: *(Attach any pertinent documents, like a recent Regional Center IPP, or pages detailing more complicated medical issues, etc.)*

Signed by:

_____ (signature)
_____ (print mother's name)

_____ (signature)
_____ (print father's name)

A copy of this letter was given to: