

# Who Will Care for My Child When I'm Gone? A California Parent's Guide to Letters of Intent



If you are raising a child with a disability, you may have asked yourself a question that is difficult to say out loud: **Who will understand and care for my child when I am no longer here?**

You may already have a will or trust. You may have named family members who love your child. But would those people know your child's daily routines, communication style, medical needs, favorite activities, or the best way to respond during a difficult moment?

That is where a **Letter of Intent** can help.

A Letter of Intent is one of the most practical tools in **special needs planning for families**. It helps future caregivers understand your child as a whole person, not simply as a list of diagnoses, benefits, and legal documents.

## What Is a Letter of Intent?

### Is a Letter of Intent a legal document?

**No.** A Letter of Intent is not a will, trust, power of attorney, or legally binding instruction. It does not appoint a guardian, name a trustee, or override the terms of your estate plan.

Instead, it is a detailed, practical, non-binding guide for the people who may care for your child in the future.

Think of it as a roadmap. Your legal documents establish the structure: who manages money, who may serve as guardian or conservator, and how assets should be distributed. Your Letter of Intent explains how your child's life actually works from day to day.

A future caregiver may know that your child has autism, cerebral palsy, Down syndrome, or another disability. But that diagnosis alone does not tell them:

- How your child communicates discomfort
- Which foods or textures your child avoids
- What helps your child feel calm
- Which medications have caused side effects
- How your child likes to spend free time
- Which people are especially important to your child

**Your Letter of Intent fills in those essential human details.**



## **Why Does Your Child Need More Than a Trust?**

### **Could a special needs trust answer all of these questions?**

A **special needs trust for a child with a disability** can be an important part of your plan. It may hold assets for your child while helping preserve eligibility for certain public benefits, depending on the trust structure and current program rules.

But a trust document is not designed to explain your child's bedtime routine or identify the therapist who knows how to help during a crisis.

A trust generally addresses questions such as:

1. Who will manage the trust?
2. How may trust funds be used?
3. Who receives any remaining assets after your child's death?
4. How should the trust coordinate with public benefits?

Your Letter of Intent addresses a different set of questions:

1. What helps your child feel safe and understood?
2. What does a typical day look like?
3. Who are your child's medical providers and trusted friends?
4. What are your hopes for housing, education, work, and community life?

**The trust protects financial resources. The Letter of Intent protects continuity, familiarity, and quality of life.**

The two documents should work together, but they do different jobs.

## **What Should You Include in a Letter of Intent?**

### **What would a new caregiver need to know on the first day?**

There is no single required format. Your letter should be personal, practical, and detailed enough that someone unfamiliar with your child can begin providing consistent care.

Consider including the following sections.

#### **1. Basic information and your child's story**

Start with information that helps a future caregiver get oriented:

- Full legal name and preferred name
- Date of birth and current address
- Recent photograph
- Diagnoses and relevant medical history
- Allergies and emergency information
- Communication style, including sign language, an AAC device, or picture communication
- Strengths, interests, personality, and preferences

This is also a good place to describe your child in your own words. What makes your child laugh? What are their talents? What do you want others to notice first?

#### **2. Daily routines and personal preferences**

##### **Why does routine matter so much?**

Many children and adults with disabilities rely on familiar routines to feel comfortable and confident. A sudden change may be confusing or distressing.

Describe a typical day, including:

- Wake-up and bedtime routines
- Dressing and personal-care preferences
- Favorite foods and food sensitivities

- Mealtime positioning or assistance
- School, work, or day-program schedule
- Preferred activities and hobbies
- Screen-time routines
- Transportation needs
- Strategies that make transitions easier

Be specific. “She does not like loud environments” is helpful. “She becomes overwhelmed in crowded rooms and does best with noise-reducing headphones and a quiet break” is even more useful.

### **3. Medical providers, medications, and therapies**

List the people and services involved in your child’s care:

- Primary-care physician
- Specialists
- Dentists
- Therapists, including occupational, physical, and speech therapists
- Behavioral-health providers
- Pharmacy and preferred hospital
- Medication names, doses, timing, and purpose
- Known side effects or medications that did not work
- Therapy schedules and current goals
- Emergency protocols

Keep copies of important medical records and care instructions with the Letter of Intent, while protecting private information appropriately.

### **4. Communication, behavior, and support strategies**

#### **What happens when your child cannot explain what is wrong?**

Your letter should explain how your child communicates needs, discomfort, fear, or excitement.

Include:

- Words, gestures, signs, or devices your child uses
- How your child indicates pain or illness
- Common triggers for anxiety or distress
- Early signs that your child is becoming overwhelmed
- Calming techniques that work
- Approaches that tend to make things worse
- Sensory sensitivities involving sound, light, clothing, touch, or crowds

This information can help a new caregiver respond with patience and confidence rather than treating unfamiliar behavior as defiance.

## How Should Benefits and Financial Planning Be Addressed?

### Could an inheritance accidentally disrupt benefits?

Many parents assume that leaving money directly to their child is the simplest solution. Unfortunately, a direct inheritance or large gift may affect eligibility for needs-based benefits.

As of **August 2026, California Medi-Cal asset limits are \$130,000 for an individual and \$195,000 for a couple**. Eligibility rules can vary by program and household circumstances, and other benefits, such as SSI, have separate resource rules.

For current guidance, review information from the [California Department of Health Care Services](#) and consider how your child's benefits interact with your estate plan.

Your Letter of Intent should identify:

- Current benefits, such as SSI, Medi-Cal, IHSS, or regional-center services
- Caseworker and agency contact information
- Benefit identification numbers, stored securely
- Any CalABLE account
- Current representative payee or benefits manager
- The location of your trust and estate-planning documents
- Instructions that future caregivers should confirm current rules before receiving or transferring assets

A properly drafted special needs trust may help hold funds for your child without treating those assets as personally owned resources. However, the trust must be drafted, funded, and administered carefully.

**Your Letter of Intent can explain your goals, but the trust document controls legally.**

## What Role Does the Letter Play in Long-Term Care?

### Who should your child live with in the future?

You may have strong preferences about your child's housing and support. Record them clearly, while recognizing that circumstances may change.

Describe your preferences for:

- Living with family
- Supported or independent living
- Group homes or other residential programs

- Roommates and neighborhood setting
- Proximity to relatives, friends, and familiar providers
- Accessibility modifications
- Transportation
- Education, employment, or adult day programs
- Religious, cultural, recreational, or community activities

Also identify important people in your child's life: siblings, grandparents, friends, mentors, teachers, support staff, and neighbors. Include how often you hope those relationships will continue.



## How Often Should You Update It?

### Can you write the Letter once and put it away?

It is better to treat your Letter of Intent as a **living document**.

Review it whenever there is a significant change, such as:

- A new diagnosis
- A medication change
- A new school, job, or day program
- A change in housing
- A change in benefits
- A new caregiver or service provider

- A change in communication or behavior
- A major change in your child's preferences

At a minimum, review it regularly and date every version. It should be reviewed alongside your special needs trust and broader estate plan so your practical instructions and legal documents continue to work together.

At Pele Law Group, complimentary plan reviews every three years are available **exclusively to clients who have already completed a special needs trust or estate plan with our firm**. We also offer trust amendments and ongoing support for clients whose original special needs trust or estate plan was prepared elsewhere.

## What Should You Do Next?

### Are you waiting because the conversation feels overwhelming?

You do not have to complete everything in one weekend. Begin by writing down what a new caregiver would need to know during your child's first week without you.

Then consider whether your legal plan supports those instructions.

A complete plan may include:

1. A will and appropriate trust structure
2. A special needs trust, when appropriate
3. Guardian or conservator nominations
4. Health-care and financial powers of attorney
5. A current Letter of Intent
6. Information about benefits and service providers
7. A process for reviewing the plan as your family changes

At Pele Law Group, we approach **special needs planning for families** with both legal knowledge and an understanding of the emotional realities involved. If you are looking for a **special needs trust attorney in California**, we can help you identify what needs attention and what options may fit your family.

You can [book a free 15-minute discovery call](#) to discuss your concerns and decide whether our planning process is a good fit. We serve families virtually throughout California and can also help with amendments and ongoing support when your existing plan was created by another firm.

**You are not trying to predict every detail of your child's future. You are creating guidance, structure, and reassurance for the people who will help carry your care forward.**

