



Letter of Intent Gives Valuable Advice to Future Caregivers

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Parents of children with special needs have lots on their plates. When it comes to estate planning, the tasks at hand can be complicated, and the choices parents have to make – how to provide for their child’s needs when they are not around and whom to name as fiduciaries to step into their shoes – can be overwhelming. The idea of leaving behind a detailed list of caregiving minutiae may fall to the wayside. But on top of executing the right legal documents and identifying the best person for each role, parents should not forget to [include a Letter of Intent \(a “Letter”\) as part of their plan](#).

Parents know the details of their child’s life, including medical and educational history, moods, allergies, sleep habits, fears, favorite foods, clothing size, and day-to-day needs, like no one else. No legal document—special needs trust, guardianship or [advance directive](#)—can fill that gap. A Letter, however, can minimize the learning curve and disorientation when trustees and other caregivers assume their new responsibilities. As a result, the Letter may be one of the most important parts of special needs plan.

A Letter should be easily accessible and include some, if not all, of the following topics:

Family and Friends: A Letter should include contact information for all relatives and friends who play an important role in the child’s life. Parents should describe sibling relationships and identify those persons who are most likely to step up during times of need.

General History: Parents should provide a general history of their child’s life to date. They might also include their desires for the future and how those may differ from their expectations for their other children.

Medical Care: A Letter should include a detailed medical history and health insurance information. This section should outline current medications, physicians, therapists, preferred hospitals, allergies, assistive devices, blood type and the frequency of different appointments. Parents should also explain what treatments have proven ineffective in the past.

Mental Health and Behavior Management: If a child has behavior management and/or mental health concerns, the Letter is a good place to explain what approach has worked

best in the past. What motivates the child? Does he or she have triggers, and, if so, what is most comforting?

Diet: If a child has food allergies or adverse interactions with medication, include that information here. List also favorite foods and tips for preparation and serving.

Agency Services: Explain what services the child receives from local agencies and provide contact information.

Daily Living Skills: A Letter should include information on the child's daily skills, including the need for assistance with cooking, toileting, bathing, dressing and shopping. Parents should describe any individualized programs currently in place and safety concerns, if any.

Public Benefits: Parents should describe all government benefits received or anticipated in the future, including any insight into eligibility criteria. The Letter should include a record of the award history from the Social Security Administration or Medicaid, contacts for caseworkers, important dates and reporting requirements. If the child is on any waiting lists, include that information here.

Private Financing: If the child has regular expenses that are not covered by government programs, include information on how are those expenses are funded (and might be funded in the future).

Education: Parents should describe their child's educational experience to date and their vision for the future. Are there specific classes or schools the parents would like to target? Does the child have aspirations to attend college? Should the emphasis be on academic or vocational skills? What about living skills and extracurricular activities? A Letter might also include a copy of a current or recent Individualized Education Plan, or IEP.

Residential Environment: The Letter should describe the child's current living arrangements and whether those arrangements are likely to change in the future, when the parents are no longer around. What would be the best alternative—a group home, supported apartment living, subsidized housing, or something else? Parents should spell out where they are in the process of making any housing arrangements and whether their child has strong preferences.

Employment: If a child is employed, include that information here. If not, parents might consider writing down what type of job and work environment they think their child would enjoy, and the steps necessary to reach that goal.

Social Life: The Letter should include a section on social life that addresses family celebrations, friendships, recreational activities, hobbies, vacations and travel companions. Have the parents considered issues around dating and intimacy? What role

does religion play in their child's life? All of these are topics on which a trustee may have little to no information, but which may make up a large part of the supplemental expenses paid by a special needs trust after the parents are no longer around.

End of Life: Lastly, a letter might explain funeral preferences and include details of any arrangements the parents have already made. If there is a family plot in a local cemetery, include that information here. Include also a copy of the child's living will or end-of-life wishes, if any.

Parents should sign and date the Letter, and let future caregivers know that it exists. A Letter should be kept in an easily accessible location and with other important documents. If parents have an estate planning attorney, they might request that a copy be kept with their original estate planning documents. The Letter should be updated each year, and parents might involve future caregivers or fiduciaries in that important process.

Families with special needs have long, stressful days, so it can be tough to focus on the admittedly emotional undertaking of preparing a Letter of Intent. It's not necessary for parents to complete a Letter all at once, but getting started as early as possible is a good idea. Parents should take the time now because if designed well and updated regularly, a Letter could reduce the emotional and logistical disruption that will inevitably occur when they are no longer able to care for their child.

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