

Information of interest to people with disabilities and other special needs and their families.

Your Letter of Intent: A Guide to Caring for Your Loved One

One of the most useful documents to have on hand when you have a child (or spouse) with special needs is a completed Letter of Intent. Yet as valuable as it is to have, many families – regardless of their good intentions – don't have one. It takes time to complete, needs routine updating, and can lead some parents into conversations they've been avoiding. So why do it?

What is a Letter of Intent?

A Letter of Intent (LOI)¹ is a living document – that is, you'll continue to make changes to it over time. It provides a variety of information, primarily about your child (or other family member) with special needs. While it isn't binding in a court of law, it does provide guidance to those who may make decisions regarding the interests of your loved one, which means your intentions are more likely to be carried out even if you're no longer in the picture.

"The document fills in the missing blanks for a person who may not know your child well enough to fully step into the caregiver role," explains Kenneth Prodger, ChFC, CFP² who has earned the Chartered Special Needs Consultant (ChSNC)³ designation and is a Special Care Planner with Miceli Financial Partners Wealth Management and Insurance Services⁴ in San Jose, California, a general agency of Massachusetts Mutual Life Insurance Company (MassMutual). "The intent," he adds, "is for potential guardians and caregivers, individual or corporate trustees, judges, and others to

have some guidance when they have to make decisions that affect your child. For example, if your family took annual trips to a favorite vacation spot, and that's mentioned in the LOI, a trustee who receives a request from a guardian for funds for the trip would understand that it's a reasonable expenditure."

Information included in an LOI

You'll better understand the value of an LOI when you know what's included in it, so let's take a look.

First, you'll provide general information about the parents of the person who'll benefit from the LOI – names, addresses, and other contact information, social security numbers, dates and places of birth, languages spoken, religion, citizenship, and marital status. The document also asks for information about the parents' living siblings and other pertinent biographical info.

The next section is about the person with special needs – siblings (including which are closest geographically and emotionally), significant friends and family members with contact info and descriptions of the relationships, guardians, advocates, trustees, and other named individuals who'll help make decisions for or care for your child, and final arrangements, if made.

Other sections ask you to provide additional details about the person with special needs:

- medical history,
- current housing information and future wishes or potential needs,
- daily living skills and behaviors, including finances, sleep habits, personal behaviors, triggers, and so forth,
- participation in day programs or employment,
- education,
- leisure and recreation activities, including people involved, likes and dislikes, and favorite things, places, and activities,
- religion and related memberships, as well as rights and values expected based on religious beliefs (such as properly attired caregivers, medications and treatments, non-offensive language, etc.),
- services and benefits the person receives,
- a photo of the person,

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- and general comments you may want to make to give caregivers, professionals, or other decision makers further insight into the person.

Not an easy task

“For parents, this is the most difficult part of creating a life care plan⁵,” says Prodger. “There’s a great deal to consider. Who’ll be your child’s future caregivers? What must they know to do the job as well as you have?”

It can be overwhelming because of the volume of information. You’ll need to research facts, such as contact info for medical providers and dates and places of treatments. It can also be emotionally challenging because of the decisions you’ll have to make, such as naming a guardian or trustee, or simply because you must think of your child living without your care.

Prodger, other Special Care Planners, or perhaps your own financial professional can help you complete the document, taking one step at a time. Once it’s done, it’s relatively easy to maintain.

“I’ve had parents tell me it was much more difficult than they thought it would be,” says Prodger, “but they’re so happy to have it completed.” There’s a sense of accomplishment and relief to have it done, to know your best intentions for your child are formalized and available to others. Getting it done falls into the realm of parental responsibility, but it might also be thought of as an act of love.

Some helpful tips

- Before you begin, read it through, making a list of what you’ll need to research before completing the sections.
- Don’t try to do it all in one sitting.
- Ask a friend or your financial professional to make reminder calls to you as you work to complete it. It’s easy to put the document aside and forget it; the reminders will keep you on track.
- Look at it from point of view of having to take over the daily care of a friend’s child. What would you want to know so you can do the best job? This perspective may help you remember what you should include.
- Be honest. If something isn’t important to you, don’t make it one. On the other hand, don’t convince yourself something’s unimportant when in reality it’s an issue you’re trying to avoid.
- You and your spouse may not agree on some issues. Be prepared to have tough conversations and to work together to come to the best decisions.
- Remember to include highlights of your child’s life. If horseback riding therapy or an occasional train ride or a particular ice cream is a joy, include it.
- Just as important to include are dislikes and trigger mechanisms, especially if they cause negative behavior.
- Completing as much as possible before meeting with an attorney (to create a will, a special needs trust, or other family trusts, for example) will help you be more confident about the decisions you’ve made and better prepared for an efficient and effective meeting.
- Realize it’s a living document. Update it as needed.



Keeping it up-to-date

Whenever there's a change that causes the LOI to be incorrect or incomplete, it should be updated. "You're probably dealing with a lot of medical issues – a new speech therapist, a relocated doctor's office, or a newly prescribed medicine or treatment," explains Prodger, "so you'll update it fairly often based on that." Many other changes are event driven – an updated IEP, a birth, death, or divorce, or a guardian is no longer able to assume responsibility." You may not always remember to update the document, so you might want to mark your calendar and review the document every six months or so.

As a person ages, new triggers may develop, and likes and dislikes may change. If the LOI is for a child who is high functioning and can verbalize his or her wishes, your child may want to have a say as he or she ages and may want to take over maintaining the document when he or she becomes an adult.

A few more things you should know

Remember that this is a confidential document. It contains social security numbers and other facts you may not want widely distributed. "If you created it on your computer, you may want to transfer it to a USB flash drive in case your computer is hacked or crashes," Prodger suggests. "Keep a current copy in safe deposit box with other important documents or in a locked, fireproof container in your home."

Once completed, an LOI is an excellent resource for you to use for other forms or questionnaires you'll inevitably be requested to complete for medical professionals, service providers, government benefits programs, etc.

Lastly, you may want to consider completing an LOI for all your children. It could be helpful if a guardian must step in to provide care when your children are quite young. Additionally, the document could be useful to your children when they're adults since it will provide their complete childhood medical history.

1. A Letter of Intent template is available for free from MassMutual. Please visit www.massmutual.com/specialcare and click on "contact us" (in the blue bar) to send an e-mail request. Be sure to include your name, mailing address, and phone number.
2. www.kenprodger.com
3. Chartered Special Needs Consultant - a professional designation awarded to those individuals who've completed 120 hours of academic classes and hold a CLU, ChFC, MSFS designation in addition to previously completing the Special Care Planner certification program. The designation was developed by The American College in Bryn Mawr, Pennsylvania. The certification program and the professional designation evolved from MassMutual's SpecialCareSM Program.
4. www.micelifinancialpartners.com
5. A Life Care Plan is a coordinated program of future care planning, financial and legal strategies for people with disabilities and their families. A Life Care Plan continually changes throughout an individual's lifetime and is provided by a team that may include your legal and tax advisors as well as insurance and investment professionals.

* The Special Care Planner received advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with disabilities and other special needs and their families. The certificate program was offered by The American College in Bryn Mawr, PA, exclusively for MassMutual financial professionals. State insurance departments recognize that the Special Care Planner certificate program provides essential information on the profession of special care by granting continuing education (CE) credits (varies by state).

A Special Care Planner through MassMutual's SpecialCareSM program can assist parents in drafting Letters of Intent and can help make a difference in the quality of life for an individual with special needs, their caregiver and other family members. Through SpecialCare you will learn valuable financial strategies, identify financial strategy solutions, access vital information, and meet certified specialists who will work with you and your professional advisors – your banker, accountant or financial planner, lawyer, social workers and health care providers – to review your financial picture and offer options to fit the needs of each situation. For more details, visit MassMutual's website at <http://www.MassMutual.com/specialcare>, or call 1-(800)-272-2216.

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