

ALWAYS ON MY MIND: My Special Needs Child

A Letter of Intent Brings Peace of Mind

By Kristi Sweeney, CFP®

No matter what the age or disability, parents of children (or adults) with special needs have many serious questions about how best to provide for their child's future well-being. These are unusually difficult decisions regarding the welfare of your child. The most important of these is probably how to provide for ongoing care after your death. In this article, we will explore how to prepare future caregivers with a Letter of Intent.

It's not easy to think of what will happen when you can no longer care for your dependent. How can you prepare your trustee and caregivers for the day when they will take over the care of your child? If you are fortunate to have a reliable, loving family member named as trustee, you may feel this step is unnecessary. You may believe they are already quite familiar with your intentions for your child. But are they? Do they know that your child hates peanut butter because it sticks to the roof of his mouth? Does your trustee know that your child likes red and blue shirts without buttons? Does anyone but you know the activities your child prefers or how he reacts to certain situations? A Letter of Intent, carefully prepared and updated, will communicate what you know best to the important people in your child's life.

A Letter of Intent is an important document. Although not legally binding, this document provides often very welcome direction and guidance for the person or persons who will be involved in the day-to-day care of your dependent with special needs. This special document is a working document when your child is growing, maturing and changing. Think of it like a letter that you write for a babysitter when you go out for one evening and it becomes easier to get started. When you are finished, a Letter of Intent will provide instructions when you "go out" forever. It is hard to think of that possibility. Putting together one's plans for the future of a child with special needs can be a cumbersome task loaded with emotions. Rest assured that your reward will be relief and peace of mind once you are finished.

Include vital information regarding your child's physical and mental status. The Letter of Intent should include your child's

likes and dislikes, hobbies, recreational and social preferences, food allergies, medications, physicians, medical history. You will also want to include your hopes, dreams, wishes and aspirations for his or her future. It should detail your thoughts on a variety of matters such as dating, religion, sex, future living plans, and academic and job-readiness skills.

Most people start their Letter of Intent with vital statistics. Include your child's full name, nickname preferred by your child, date and place of birth and Social Security number. A current photo and information such as height and weight is also useful. List the names of family members, your child's guardian, executor of your will, trustee, advocate, financial advisor, vocational contact, government or benefit contact, social service organizations that you use as a support and anyone else involved with your child.

It is very important to record all facets of your child's medical condition and developmental histories and to provide access to all records. Without proper records and documentation, future caregivers may not know what the important issues were and what services worked best for your child. For instance, list behavior challenges and typical interventions, past surgeries, favorite foods and also food dislikes. Are there any food intolerances or allergies?

Attach current copies of your child's education plan (IEP) if your dependent is in school. Include testing and evaluations. When these documents are all in one place, it will be easier for a caregiver to provide continuity.

You might not think of this, but include your child's shoe size, clothing preferences and any special adaptive devices needed.

As direction to the financial trustee of a discretionary supplemental needs trust (you can't actually direct the trustee, but your suggestions will be appreciated), outline how you want funds to be spent on your dependents behalf. Do you want him or her to be able to take a trip to visit family? A big screen TV.? Piano lessons? What are your priorities? Do you want your child to have some spending money? He or she will not become disqualified from government benefits as long as your child does not have \$2,000 in assets.

The Letter of Intent can be prepared in almost any format. I like the idea of a letter on the computer that can be modified at any

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time. But other people like taped recordings and videos. Most importantly, it must stay current. Updating every year or whenever there are changes is critical.

Many people include feedback from those who are closest to their child with special needs. In fact, you may want to make it a family affair by including your special needs child if it would be appropriate. Depending on your child's abilities, he or she should have as active a role as possible in helping you determine what will be the best course for his or her future. If you bring this up with an older child or an adult dependent, together you will come up with ideas and options that you might not have thought of previously.

You will know that the kind of loving care your child would want has been communicated to the trustee, the co-trustee or guardian and all the other people who will be important in your child's life when you are no longer able to be his or her advocate.

Kristi Sweeney is a Certified Financial Planner Practitioner with seventeen years of experience. Her business, Sweeney & Associates, LLC, is located in Greenwood Village, Colorado. Kristi belongs to several estate and financial planning associations and has comprehensive training and experience in special needs planning.

Kristi presents frequently at educational estate and financial planning workshops. Having a family member with a disability, she regularly assists other families with planning issues when they have dependents with special needs. A Letter of Intent in outline form is available at your request from the author's office. Please call #303-773-0200 or email kristis@sweeneyassoc.net.