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# Strategies For Families With Special Needs

**S**ome clients are more demanding than others. Often it's not that the clients are hard to please, it's just that the breadth of their needs is more challenging. That's certainly the case for families with disabilities.

According to the U.S. Census Bureau, there are 77 million people age 5 and older in the United States who have a disability. That's nearly 1 in 5 American residents. The President's Committee for People with Intellectual Disabilities reports nearly 8 million of them are developmentally challenged. Furthermore, the National Alliance of Mental Illness documents that 20 million adults and 6 million children have a mental illness defined as "serious," and an estimated 4.5 million Americans have Alzheimer's disease.

The population of people with disabilities is growing steadily, mainly due to medical advances that enable them to live longer, as well as the aging baby boomer generation. For the first time in history, people with disabilities have a greater likelihood of outliving their parents and guardians, which is why it is imperative to plan for a loved one's future. Families need to make sure everything is in place so, after they're gone, their loved one can still live a quality life.

But the current situation surrounding people with special needs is disheartening. According to a survey released this past spring by MetLife, 88 percent of parents of people with disabilities do not have a special needs trust. Add to that the fact that 84 percent have not written a letter of intent, 73 percent have not identified a trustee to take care of the person's finances, and 52 percent have not selected a guardian in the event of the parents' death.

All this special needs planning can be

paralyzing for families and overwhelming for planning advisors. These families have needs that go beyond standard insurance planning considerations. Unique legal and financial issues pertain only to people with disabilities, such as establishing the special needs trust fund so necessary government benefits are captured. Too few insurance brokers have the training to take on the complexities of such cases and, if trained, they have little support to manage these clients.

The first special needs family I provided guidance to was my own; my younger sister suffered severe mental handicaps due to cerebral palsy. For years, I struggled with the torrent of misinformation that's bound to confuse any financial advisor. But after 15 years experience, I've learned every aspect of serving the special needs community and have advocated for thousands of other families with disabilities.

I have learned that to properly serve a special needs family you need to be more than just a financial advisor. You need to be a life coach. For these families, life is about doctors, teachers and service agencies. Each of these families needs a life coach to look into all components of their world: legal options, potential benefits, investment and life insurance solutions, residential choices, employment preferences and recreational opportunities. I have discovered that eight steps are needed to fully serve a family with special needs.

One step often overlooked, but so crucial for future care, is a letter of intent. The document chronicles the loved one's likes and dislikes, special stories and talents, and the necessary medical and educational history. I created a fill-in-the-blanks booklet called "My Special Life" that helps families in this process. The

## A Step-by-Step Plan for Families with Special Needs

Ehler's company has developed a step-by-step plan for families with special needs, entitled "Process for Protected Tomorrows." Following is the eight-step plan.

1. **Take a Candid Look.** Look comprehensively at your special needs client's future care needs, in light of the entire family.
2. **Create the Future Map.** Identify the options and create a plan to protect the individual with a disability and the entire family's future.
3. **Filter Legal Options.** Evaluate and execute estate solutions, focusing on the various options available through professional legal resources.
4. **Capture Potential Benefits.** Identify and apply for supplemental programs to enhance and supplement the future care plan you have created for your client.
5. **Document the Wonder.** Encourage the family to chronicle and treasure their loved one's special story to pass on to a new caregiver.
6. **Begin the Transition.** Identify and evaluate the future residential, employment and recreational options for the special needs client.
7. **Fund the Future.** Utilize insurance and investments to complement the future care plan.
8. **Renew and Review.** Review the future care plan annually to address life's inevitable changes.

information is passed on to the next caregiver in the event the parents or guardians die.

The client with special needs can be a child, an adult or an elderly individual. Some of the disabilities in the families with whom specially trained "advocates" and I assist include: Down syndrome, cerebral palsy, autism, Angelman syndrome, bipolar disorder, schizophrenia, Alzheimer's disease and amyotrophic lateral sclerosis (Lou Gehrig's disease).

The network of advocates that I have trained and licensed provides a continuum of care. The first question we ask is not "What are your assets?" but rather, "How would you like your life to look?" Then, a life strategy begins to unfold. Money is a tool, not the impetus.

What drives the life plan are the person's abilities and what is necessary to surround him with appropriate care. For example, a young adult might desire to live in his own home, and he could do that with the help of a caregiver. There are agencies funded by government programs to meet that need. We get families connected to those service providers.

Also, if the special needs individual were capable of working in the community, we would assist that person with finding a job coach to help in that process. Along the way, the advocate researches the cost of these services and whether they are government funded.

**There's a lot of misinformation on special needs planning.** Many people are not cur-

rent with changes in the law, access to social services and available government benefits. Quite often, the special needs person relies on those benefits for their daily expenditures. Advocates do the job of sifting through the quagmire to find solutions.

So consider broadening your services to families with a disability to meet all of their needs, not simply their financial ones. You will not only gain greater client loyalty, but also add new meaning to your work.

**Here are some basic steps to help reach out to the special needs community in an effective way.**

**Find a connection.** Planners likely know someone with a special need. Make new clients aware of that fact, so you're more relatable. Also, plug into organizations and agencies that service the disability community so you are more aware of their needs. Again, make it known to your clients that you have attended these seminars or events and, of course, share the fact that you are a member.

**Ask the right questions.** First, learn about the hopes and dreams of the family. Most clients have never talked about this outside the family and usually will open up once the conversation starts. You will glean much information about the direction of planning from this initial conversation.

**Network and refer to other appropriate professionals.** Attorneys, benefits specialists and officials from local programs—educational, recreational, residential, medical—are

experts in their fields to help both the planner and family (another advantage to familiarizing yourself with the disability community).

**Research all financial options.** Utilize insurance and investments, but also explain the importance of setting up a special needs trust and securing government benefits. Don't simply look at available money and potential earnings. Avoid setting up uniform transfer to minor and guardianship accounts to be owned by the person with special needs. You could disqualify the individual from valuable options in the future.

**Communicate regularly.** Laws and government benefits change often, almost as quickly as the stock market. Also, when the special needs child is between the ages of 18 and 25, there are a number of transitions that take place—guardianship/conservatorship, residential, asset management—so emphasize to the client that an ongoing relationship over the years is in the best interest of the child.

### Taking on Clients with Special Needs Demands a Different Vocation

Every day I make a difference in someone's life. I invest my time, my heart and my mind. As an advocate, you become emotionally tied to your clients. It makes you a more complete advisor. When the independent insurance professional acquires the requisite knowledge and understanding of the special needs family, a comfort level develops between them and their client. With comfort comes trust. With trust comes loyalty, referrals and more clients.

Life planners specially trained to serve this community have seen the rewards both personally and professionally. One example is an investment advisor in Lawrence, KS. Within a year of incorporating my eight-step planning process into his practice, the number of his clients with special needs increased from 5 percent to 50 percent. Many other professionals are seeing success as the demand grows for this type of expertise.

The special needs population represents a vast and underserved community that needs more qualified life planners and advocates. The market is unlikely to change in the near future, especially since the aging of baby boomers will result in more families likely to need an advocate to guide them through that season of life.

Besides the obvious additional income to your firm, the most significant and satisfying benefit to gaining knowledge and opening your practice to this demographic is the personal gratification that comes from serving individuals with special needs and their families. ☺