

10 Questions

WITH NOTEWORTHY PEOPLE

Mary Anne Ehlert on the Myths, Challenges, and Role of Advisers in Special-Needs Planning

by Bruce Most



Who: Mary Anne Ehlert, CFP®

What: Founder and president of Protected Tomorrows and Ehlert Financial Group

What's on her mind: "When you find special-needs families who need help, it's very gratifying to help them. They become very solid clients, because you're helping them in a way that perhaps other aren't."

If you think having clients with a special-needs family member is rare, think again. More of your clients likely require special-needs planning than you realize, says Mary Anne Ehlert, CFP®, a financial planner who specializes in special-needs clients. According to the 2000 U.S. census, one in five people in this country ages 5 to 64 are designated as having a disability. That means they depend on others for some or all of their care and support. They may be blind, autistic, have Down syndrome or Lou Gehrig's disease, or any one of a host of other mental or physical disabilities.

The population with disabilities is growing. Whether because of more accurate diagnoses, something in the environment, or both isn't clear, says Ehlert, whose younger sister died of cerebral palsy at age 39 and who also has a blind and mentally ill stepson. For example, autism, once considered rare, now is diagnosed in one out of 125 births—and one out of 70 boys! People with disabilities are living longer and more productive lives, necessitating longer-term care. Where people with Down syndrome once didn't live long because of heart issues, now families need to think about providing senior care for them.

Ehlert started her own RIA financial plan-

ning firm in 1990. Forty percent of her clients require special-needs planning. Operating out of a 17,000-square-foot converted warehouse in the Chicago area, Ehlert oversees a suite of companies and tenants oriented toward special needs. Her own organizations include her financial planning firm, an advocacy group called Protected Tomorrows, an architectural design firm for special-needs housing, a nonprofit Special Needs Network, and a special-needs career consulting division. The facility also is home to a chapter of the Illinois Special Olympics, an image-consulting firm that helps those with disabilities prepare for employment, and a law firm with expertise in special-needs planning.

We talked to Ehlert about how she got involved in special-needs planning, the challenges faced by special-needs clients and their financial advisers, and how the financial planning community is, and is not, responding to this need.

1 *Your background is in computers, banking, and financial planning. Why did you become such a passionate advocate for special-needs planning?*

I had a sister with cerebral palsy and I was very, very close to her. When I started my

financial planning business, I asked my parents what they wanted me to do in case something happened to them and whether they had done their estate planning. They told me they had disinherited my sister and left her share of the inheritance to me, along with instructions that if something happened to them I would step in and become her guardian.

I really didn't understand why they had done that. That's when I found special-needs attorneys and got involved with

Social Security and the Department of Human Services, trying to find out the rules. I found that my parents had not gotten proper advice. As I began working with special-needs families, I found that most of them had not done planning, or had done improper estate planning and didn't understand why they were doing it. So I helped them on the estate planning piece. But as I finished their estate planning, their question was, "Now what?" They had found someone who would listen

to them and pay attention. Most of these families felt very alone and very confused. Soon I was actually applying for SSI [Supplemental Security Income] and Medicaid on their behalf, becoming their representative. I was helping them go into companies, asking for jobs for them, and trying to find them housing.

2 *What are some of the unique challenges families and their advisers face in special-needs planning?*

Confusion is the biggest one—and that they don't know what they don't know. The parents' biggest fear is not to do with money, but with who is going to take care of this person when they're gone. Parents get paralyzed at the thought of someone stepping into their shoes, because it's such a consuming job. You don't want to give that job to someone else, but you will, because you must. That's the biggest concern we hear.

Just getting proper advice is another challenge. They can't put money in this person's name and save as you can for your child going to college. We end up with a lot of cases where a family comes to us and wants us to help them get SSI and Medicaid. We have to undo what has been done. They might have three children and UTMA [Uniform Transfers to Minors Act] accounts, and grandma and grandpa start gifting. Suddenly, they have this special-needs child with \$100,000 in their name. That's really nice, but that \$100,000 stops them from getting Medicaid and SSI and all kinds of other programs funded by Medicaid. So we have to jump through these other hoops of putting it into payback accounts and things like that. This wouldn't have been necessary if the adviser had been versed in this to start with. Which is why we started the Protected Tomorrows training program.

3 *Protected Tomorrows describes its role as "an advocacy firm that enhances the lives of people with special needs through comprehensive planning." Tell us about the*



Talking Point

Serving Special-Needs Families

In this month's "10 Questions with Mary Anne Ehlert," a financial planner nationally recognized for her work with special-needs clients, Ehlert contends that while the financial planning community is more aware than in the past about special-needs families, it still is failing to adequately serve those families. Planners too often don't inquire of clients whether they might have a special-needs family member for whom they may or may not become responsible. Planners also mistakenly believe special-needs families won't be able to pay for their services. And planners too often make mistakes when they do serve special-needs families.

Do you agree with this assessment? What has been your response when you learned a client or potential client required special-needs planning? Have you worked with the family yourself, brought in outside experts such as attorneys, or referred the family to an adviser who specializes in this area? Discuss this and other topics at the Financial Planning Association's group site on LinkedIn (member login required).

firm and what “comprehensive planning” involves for special needs.

We formed Protected Tomorrows in 2003. The original goal was to separate the social work part from the financial planning practice, because it’s really more social work than anything else. I found that families wanted someone to be there—a coach—to hold their hand through the whole thing, no matter who does what. We have a team with some people who have financial expertise, but most are either rehab professionals or social workers. What we do is comprehensive planning or holistic planning, focusing on the person with special needs and fitting that into the family’s financial plan. We take families through an eight-step process. We don’t always follow the steps in order, but we always start with getting the facts about this individual. Disabilities are huge ranges of capabilities and financial statuses and everything else. Sometimes you have to get the family to agree on what the issues are. Getting them to put it on the table is a big step, because they have to admit it. The first meeting we talk about this stuff always involves lots of Kleenex®.

We develop that into a vision of this person’s life. Is this person going to be able to drive, dress themselves, feed themselves, all the different activities of caregiving? Where do you see them living into the future and who do you see helping them? Do you think they can or can’t work? Once we have that vision, we develop cash flows for every stage of life. There’s a different cash flow from someone who is 3, versus when they are in transition programs in high school, when they are an adult, or when the parents are gone. Then we tie that into the estate plan, making sure it is done right, that the proper information is fed to the attorney.

We get into all the things, besides financial things, the parents have to leave behind for the caregiver once they pass away, such as instructions about who this person’s friends are, who their doctors are, what they like to eat. A person with autism

may be really upset if their furniture is moved. What are the words you use to get them to behave? All the little stuff that we don’t have to do for our other children, we have to do for this person.

We find them resources. If they’re in school and they’re not getting what they should from the school, how do we find them an advocate who can work with them in the school system? Half the time, parents don’t know what their child’s rights are in the school system.

One of the steps is constantly looking at where are we today, what worked and what didn’t. You may have thought they were going to live in a certain place, but that didn’t work out, and all of a sudden you have to come up with more money. It’s a constant tweaking of the plan and education of the future guardians, just as you tweak a financial plan. It’s forever.

4 *Protected Tomorrows offers a training and licensing program for financial advisers and even nonplanners. How does the program work?*

We found that there were so many special-needs families that we couldn’t serve them all. So we started our advocacy program called Protected Tomorrows Advocates. Advisers come in for three days of classes, then a second time for two days, then for two days every year. We teach them everything we know about SSI and Medicaid, special-needs trusts, how you find the attorney and know if the attorney even knows what they’re talking about, how to take the family through the eight-step process. We become a back office for them, too, if they have questions. It’s a commitment. The licensing fee is \$5,000, the first year of training is \$10,000, and the second year is \$5,000.

What we found over time is that there are select people who can do this and the rest who want to help the family, but who don’t want to do what we do. So this year, we are kicking off a new program where we can do the special-needs part for the adviser. The adviser refers the family to us,

we’ll do the work, and send back a report the adviser can then tie into a financial plan. We work with families nationwide by conference call. The adviser looks smart and is giving their clients what they need, but they don’t have to answer the questions because they aren’t expected to know it all.

5 *We’re in the throes of a major overhaul of this nation’s healthcare system. If such legislation passes, what effect might it have on special-needs care?*

I don’t know how this is all going to end up until we see the final act. Currently, the majority of those with disabilities cannot obtain private health insurance coverage, and if they are able to purchase it, it is expensive, it carries pre-existing coverage limitations, and it has benefit limitations with maximum coverage that is often insufficient. Therefore, many with disabilities are forced to apply for Medicaid, where they lose choice of medical providers and often cannot see the specialists they may need help from. Healthcare reform may help if insurance companies are restricted from imposing pre-existing conditions on policies, if the cost of policies is limited in some way, and if lifetime benefits are not allowed to be capped. Also, some states require that if parents have a group health insurance plan and they have a disabled child who is aging out, they can keep that child on their health insurance plan. Will states change that if health insurance rules change? We think there will be a ripple effect, but we don’t know what it’s going to be at this point.

6 *In your book, The Gift I Was Given, you describe the unique interdependency that family members develop in a special-needs situation. How might that interdependency affect how financial advisers work with the family?*

To let the person you’re caring for go and have independence is a very hard thing. There is this interdependency on each other. If you aren’t in that world and don’t

know it, how do you convince them that it is in the best interest of everybody to put this independence in place when they say, “We’re just not ready yet?” You can set up all the legal provisions you want to, but it’s not always financial. It’s that the parents don’t want to act. They want to be there forever for this person. That’s their calling. I always tell parents that you can plan for the person and help them move out and have independence while you’re still around and make sure you’re there for that. The person is going to be sad when you die, but not alone because they’ll have peers around. But if you don’t do something before you die, they will be alone *and* sad.

7 *You have something called The Special Needs Network. What is that?*

It’s our 501(c)(3). Its purpose is the education of families. We do free seminars and programs. But our long-term purpose of the Network is to help families who can’t afford to get help. We also would like to set up a Protected Tomorrows type of special-needs trust company for families who can’t afford their own trust. You can’t get a big trust company to take on a \$50,000 or \$100,000 account. But \$50,000 in a special-needs trust might make a huge difference. So our goal is to set up a trust company that would be able to manage the small pots of money similar to a 401(k), where you consolidate it. You need a nonprofit affiliated as a trustee for that. That’s our plan, but it’s not going to happen yet.

8 *You’ve said that to properly serve a special-needs family one must be more than a financial adviser, that one needs to be a life coach. How can planners best serve clients with special-needs issues?*

Unless a planner is really driven, it’s a tough step to take—like any adviser who wants to add a social work component to their practice. Are they going to do some of that work? Are they really going to bring staff in to do that? It’s a staffing and education commitment. Not all people want to do that.

But we’re gearing up to handle the multitudes. We have an online system that takes people through the eight steps. So if families can’t get help one-on-one, they can use the online system with their advisers. Planners connect their clients with us and we get them online, going through the process. So the adviser is doing the financial piece while the family is working on the special-needs piece, and we’re keeping them on track.

If a planner chooses not to work with us, I think they at least need to find an attorney who does special-needs planning. That attorney will have resources, too. Find an attorney who really is authentic; verify his or her credentials so you have someone to refer clients to. Planners can go on our Web site protectedtomorrows.com. We have something called Protected Tomorrows Live. You can go on the directory and go into the special-needs estate planning category and find an attorney in [your] area.

9 *What are the most common mistakes you see financial advisers make when serving special-needs clients?*

The two biggest mistakes are no special-needs trust and accounts set up in the special-needs person’s name. The parents leave the assets to the individual in the estate plan, or to another family member—they think that’s right. Or the client says, “My child has a disability and I don’t think they can work,” so the adviser says, “You’d better start saving money for them now.” To qualify for Medicaid or other government aid, a special-needs person can only have a house, a car, a prepaid funeral, and \$2,000 in their name. That’s it. So they think they’re doing the right thing, but they’re not.

Another mistake we see is that the family has a special-needs trust, but they also have a will leaving tangible items to the person. They can’t do that. The will has to leave it to the special-needs trust. Advisers also fail to ask the question in the interview process: “Is there anyone in your family who has disabilities or special

needs?” Parents sometimes don’t talk about it. The question I always ask is, “Do you have any children, parents whom you may be responsible for, or siblings who have special needs?” It’s up, down, and around. It’s pursuing the discussions. “Tell me about them.” “Well, my sister has Down syndrome.” “Then have your parents done any planning for your sister?” I’ve had many advisers tell me that they couldn’t connect with a family about their kids. So they’ve gone back to the family and said, “I heard this presentation about special-needs planning. Is there anything in your family that might need to be taken care of? Is there anyone with any kind of disability that we should be talking about?”

10 *You’ve been in the financial planning community and serving as a special-needs advocate for many years. How well do you think the financial planning community today is serving clients with special-needs members?*

I think there is more and more awareness. But most advisers want families who can pay them and there’s a sense that families with special needs can’t. That’s not the case. That’s not true of all advisers, but new advisers certainly don’t know anything about this, and experienced advisers, once they really get busy, are managing assets. It’s not a priority. There have been lots of presentations these days about special-needs planning. But unless you ask the questions, you don’t know.

When you find families who need help, it’s very gratifying to help them. They become very solid clients, because you’re helping them in a way that perhaps others aren’t. All you have to do is ask them one or two questions and they won’t be quiet. The hardest part is getting them to stop talking. They have lots to tell you.



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