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# Special Needs, Special Planning

**Synopsis:** A subset of your clients have family members who are unable to care for themselves. Your services could get them the help they need.

Takeaways: Make sure the parents don't neglect their own financial needs. Maintain the individual's assets in trust so he/she qualifies for Medicaid, which will unlock the doors to other community programs. Redirect the gifts into the trust.

pproximately ten percent of all American families in America have one or more members who qualify as "specialneeds" for financial planning purposes," Mike Walther, of Oak Wealth Advisors, LLC, in Deerfield, IL, is telling me over breakfast at the AICPA PFP Conference in Las Vegas. "I'm shocked at our profession's lack of attention to the unique planning needs of this group," he adds.

Walther at this moment is picking through a modest breakfast that he has selected from what may be the world's longest, largest restaurant buffet, a 50-yard-long array that includes many kinds of prepared eggs, sausages and bacons, pancakes, pastries, specialty cheeses, assorted meats and seafood, cereals and oatmeal,

blintzes, potatoes, every kind of sliced fruit, yogurt and muesli, mysterious sauces, pizzas, pasta dishes, a variety of salads, bagels and perhaps a million calories

Ten percent of all American families have one or more members who qualify as "special needs" for financial planning purposes.

worth of desserts. He tells me that he doesn't consider himself an evangelist on the subject, but he has quietly become a special-needs planning resource for advisors all over the country. Walther's website (www.oakwealth.com) is a gateway to national service providers and organizations that can guide special-needs families through the labyrinth of local services.

These issues can quickly become complicated and the answers are sometimes counterintuitive.

"I got a phone call a few weeks ago from somebody who saw that I was quoted in a Wall Street Journal article," says Walther. "He's going to have to take his son out of the public schools and put him in a private school, and he's looking at a \$30,000 tuition bill." After asking a few questions, Walther told him how to have the tuition qualify as a medical tax deduction, subject to the 7.5% floor.

"If a doctor puts in writing that you need to have certain kinds of supports in the classroom," Walther explains, "and your public school district cannot or will not provide them, and you have to pay out of pocket for those things, they become medical deductions for tax purposes. Walther walked this person through the documentation "But the second part, process. which I think trips up a lot of clients, " he says, "is that he has to keep records of everything he spends money on. A lot of people don't know what is an important record to keep, and as a result they can lose valuable deductions."

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Walther's interest in specialneeds planning started early. His brother has been diagnosed with a mild variant of autism called Asperger's Syndrome. "When we were growing up, he was sent to a cerebral palsy institution in St. Louis, where they told my parents that he would never walk or talk," "They failed to accept he says. that. They said, let's see if we can't

do better than they are telling us."

of questions. It turned out 97% of those kids were happy. Try to find a number like that in any other population."

Walther has an accounting degree, and developed a financial planning practice at Arthur Andersen in Chicago while earning his CFA and CFP designations. When Andersen folded. became a partner at what is now Altair Advisors, the planning firm founded by Steve Weinstein, Andersen's managing partner for he says. "The tendency is to shy away from asking, because they aren't sure how to give advice in this area. You could create liability for your firm if you know there's a special-needs issue and don't address it properly."

You have to keep asking, because special-needs situations can pop up at any moment. "Recently, one of my traditional planning clients had a grandchild born with Down's Syndrome," says Walther. "Another client had adopted a child, and he started really acting out when he reached high Through psychological school. evaluation and medical testing, we discovered that he had fetal alcohol syndrome."

deployments with post-traumatic stress syndrome or physical and mental disabilities that make it hard to work. motorcycle accidents can result in mental impairment.

Chances are, you'll discover that some of your clients have a child with cerebral palsy, Down's syndrome or autism. They lie awake at night wondering who will take care of the child when they're gone, and how they're going to pay for the care he or she receives then. "Those are the two biggies," says Walther. "And in most cases, they have no idea where to turn."

People come back from war Automobile or

## Special-Needs Advice

How do you plan for these clients? Walther starts with what not to do. "One of the most common things I come across is a family trying to dump every asset

Special-needs situations can pop up unexpectedly after the initial planning work is done.

Today, Sean fullyfunctional, possesses all of his motor skills, can write, play sports and is engages eagerly in conversation, albeit only on topics that interest him. "My parents apologized to me that I didn't have a normal brother growing up," says Walther. "But I said, this has been great for me. It has helped me better appreciate things in life, understand that not everybody is the same, and also understand how cool the world can be by seeing how he gets through life."

In fact, he says, Sean is leading a pretty happy existence. "He doesn't have all the stress that some people have," says Walther. "A recent survey was done with several thousand families who have kids with Down's syndrome, and the interviewers got in front of the kids and asked them a lot the planning division. But Walther found himself daydreaming about a different clientele than the firm was currently serving. "The paycheck was nice, the K-1s were great, and working with wealthy families was fine," he says. "But it wasn't as satisfying as I'd hoped it would be. Instead of helping someone buy a bigger boat next year, I wanted to help people get peace of mind."

Four years ago, he accepted a buyout, and hasn't looked back.

Identifying Special-Needs Clients

Suppose an advisor is not familiar with special-needs issues. Where do you start?

Walther recommends that you first identify the clients who are grappling with special-needs issues. "Very few advisors have an intake form that asks about this,"

they have into a bucket to take care of the special-needs person--which is not going to be helpful," he says. "When you're on an airplane and the stewardess tells you what to do if there's an accident and the cabin loses pressure, they don't tell you to first put the mask on the kid next to you," he adds. "You put your own mask on first, and then take care of the kid next to you.

"The very same approach has to be taken with special-needs families," Walther continues. "If you neglect yourself and your spouse and retirement and everything else, then when you get to be 70 years old, and the income stops, you have all this money set aside for your kid, and you're the one who needs help. You've created another problem."

If step one is traditional planning for all members of the family, step two is to qualify the special-needs individual for government benefits--particularly Medicaid. "If the special-needs person has more than \$2,000 in financial assets in his or her own

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1804 Garnet Avenue Suite 510 San Diego, CA 92109. E-Mail: bob@bobveres.com name, with the exception of a car and a house, they are not going to be eligible for Medicaid or supplemental Social Security benefits," Walther explains.

This is important regardless of the family's financial situation, since many of the best resources-local jobs training services, sports programs or other enrichment-are supported in part by Medicaid usually project the amount to set aside, because the answer is typically not meaningful to his clients. "I work with what's possible," he says. "If I tell most people that they're going to need \$2 million, it may not be realistically what they can afford. My answer is: if you can afford life insurance, and you can get it into the kind of trust where the government is not

Qualifying for Medicaid opens the door to a lot of other local services that are not available on a private-pay basis.

funding, and therefore cannot take on any private pay individuals. Even if the family has the independent resources to pay the full cost, that door is closed without Medicaid qualification.

The family can, however, put substantial amounts of money aside in trust for the child. How much? "It really depends on what your expectations are for the quality of life you want that individual to have," Walther answers. "Plus your comfort level that the government will be able to keep providing services."

Estimates can range from \$1 million to \$5 million. "It's typically going to be somewhere in the low seven figures," Walther says. "If someone only needs a person to check on him once day, that will obviously be a lower cost than somebody who needs 24/7 oversight."

Interestingly, Walther doesn't

going to take it at the end, you are actually creating an asset for the whole family, with the primary beneficiary being that specialneeds person."

## Attorneys and Trusts

The planning team should include an experienced specialneeds attorney who will draft the trust documents and provide guardianship advice--ideally a member of the Academy of Special-Needs Planners or the Special-Needs Alliance. Walther recommends that you interview two or three legal specialists, and have more than one relationship. "Make sure the attorney can work collaboratively," he warns. "You don't want somebody who is going to hijack the relationship. Make sure they're willing to share documents and let you know what's

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going on."

The best planning option is to set money aside in a what is variously called a third-party trust, a special-needs trust or a supplemental trust. "Essentially, this is a trust established by someone other than the special-needs individual--often a parent or grandparent," Walther explains. "It will be set up for the primary

assets are left over after death, the government has the right to bill the trust for all services it provided during the person's life. For planning purposes, that means that if the child has a third-party trust and a separate self-settled trust, you always want to spend down the self-settled trust first. If there are no assets remaining there, then the government doesn't get reimbursed.

A third type of trust, known

Many families will make the mistake
of selecting one superstar family member
as the trustee, the guardian and
everything else. But it's pretty unusual for one person
to be the best possible guardian and also the best trustee
to handle the financial management of the trust.

benefit of the special-needs person, who will never have control over the assets, and who will not make decisions about distributions." At death, any remaining assets in the trust can be designated to the benefit of any other family member or charity, wherever the family wants them directed.

Less optimal is the self-settled trust, where the special-needs individual contributes his/her own money to his/her own trust. "This is most common when somebody gets into a car or motorcycle accident," says Walther. "She may be badly disabled, with a \$2 million settlement to live on for the rest of her life."

The key difference is that with a self-settled trust, if any

as a pooled trust, functions like a self-settled trust, but is managed by a third party who pools the assets of many special-needs children. "Typically these are smaller individual trusts that are put together so they can receive more cost-effective management of the assets and better trusteeship," Walther explains. "If you have a \$30,000 trust, no bank wants to touch it."

The hardest part of the process comes when the family sits down to identify the person who will manage the trust account, and also who will function as the child's guardian in cases where he/she cannot make functional life decisions. "Many families will select one superstar family

member as the trustee, the guardian and everything else," says Walther. "But in my experience, it's pretty unusual for the same person to be the best possible guardian for the kid with special-needs, and also the best trustee to handle the financial management side of things. It's possible that nobody in their family can do either of these things well."

In those cases, Walther will have the family members talk with different community groups to find out what services these outside agencies can provide. He will look at the stability of institutions that may be required to step in and take on a primary role 20 years in the future. "Do we have confidence that the organization will be around in 20 years?" says Walther. "In the past, that might not have mattered, but with medical advances, kids with autism are approaching normal life expectancy."

## Community Resource Hunting

Finally, the team should include somebody who will help the family shop for programs and services in the community-and, sometimes, nationally-based services as well. Walther starts with the National Association for Down's Syndrome, Easter Seals, and the Autism Society--all places where the client can network on a national level and identify the local resources that are appropriate for the family's individual challenges.

"It can be very very specific," he says. "I have two clients with kids who have disabilities that I can't even pronounce. Go to the web sites for those conditions and

you find out that there are 2,000 people in the country with that problem. They have a community of folks who are facing the same kinds of challenges, and they can learn from them."

Closer to home, you may find local arts and theater programs, job and skills training facilities, therapists and hospital groups, and housing resources. To take a random example, Walther points to a recreation association that is found in most Illinois communities. "Let's say every Thursday from 6:00 to 7:00 there is a special recreation softball game," he says, "where people with special-needs are playing on the same field, with additional supports and coaches and therapists there to help the kids play the same game."

This can be a significant benefit for parents who are experiencing the burnout of 24/7 care. "It is a bit of respite for them," says Walther. "If you know your kid is going to be with this group for two hours with really highly-qualified people who have college training to work with special-needs kids, suddenly you can go to dinner, to a movie, read a book--knowing that the other 20 hours a day, you are focused on that child."

### Pitfalls and Mistakes

Walther believes that every advisor should learn about specialneeds issues, the way they learn about estate or tax planning-to be conversant, even if they don't provide the service. As a primer, he lists nine significant errors that an unwary advisor might make in

this complex field. Some of these are normal-looking advice that can become expensive mistakes for the special-needs family. Others are mistakes of omission.

1) Failure to plan for assets to go into a trust at the parents' death. "The standard estate plan leaves the assets to the spouse, and when he or she dies, they go equally to the kids," says Walther. "But that means the special-needs

I would rather give it to the other kids, assuming there are other kids to work with," says Walther, "and give other assets to the special-needs trust."

2) Purchasing cheap term insurance to fund the special-needs trust. "Term is not a good solution for permanent coverage," says Walther. "When you're 70 or 80 years old, the premiums get so high that you can't afford to pay

With medical advances,
kids with autism are living much longer lives.
You have to assume normal life expectancy,
and evaluate the durability of institutions that
might be required to step in and take on a primary role
20 years in the future.

kid receives the money directly." Goodbye Medicaid eligibility, and any programs that receive Medicaid funding.

Yes, you can turn around put the money into a self-settled trust, but the government is now going to get its share of it. "For estate planning purposes, you want to make the trust the heir," says Walther. If the parents have an IRA, the normal inclination would be to change the beneficiary designation so that it names the third-party trust. But Walther recommends that you avoid having the trust inherit 401(k) or IRA assets, because once those assets land in the trust, the trust has to spend the money back out within five years. "If you want the IRA to provide longer deferral,

for term insurance, even though your kid still has a need." Specialneeds funding is like planning for estate taxes; there is no endpoint like there is when you insure for replacement of income.

3) Drafting the special-needs trust so that it is implemented upon the second death of the parents. "If it is a springing trust at the death of the second parent," says Walther, "that means there is no special-needs trust in place until that second parent dies."

Why is this a problem? "Suppose your dad dies before you do, and he wills \$100,000 down to your kid," says Walther. "There is no trust for that money to go into because you haven't died yet." The

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money is now in the special-needs individual's hands, and has to be sent back into a self-settled trust.

Better to set up the third-party trust immediately, even it has no assets in it. Then the grandparents can target that trust with gifts or bequests.

4) Funding 529 plans or other college savings plans in the name of the child with special needs. "The 529 plan becomes a countable asset of the child in determining Medicaid eligibility," says Walther. "You lose the ability to get them onto Medicaid or Social Security at age 18."

Better to fund higher education through a separate trust, even if it doesn't provide the same tax advantages. Or, alternatively, the family could fund the 529 plan for other kids, load it up in their name, and spend some of the money on the special-needs kid if/ when he decides to pursue higher education.

- 5) Assuming the same family member should be the executor, trustee and guardian, all at once. "You want to have people with the right skillsets for each position," says Walther, "and it may well be three different people or even an outside agency."
- 6) Not communicating with all family members about your planning. "It is too easy for somebody to make a gift and mess things up for your specialneeds kid," says Walther. "Proper communication, even with difficult relatives, about what you're doing

and why eliminates the problem and gets everything into that third-party trust."

7) Failing to communicate, in detail, how someone should care for the special-needs individual after the parents or caregivers are gone. "Everybody should draft what we call a care guide," says Walther. "It should say, in the family's own words, all the important real-world things that somebody would need to know to provide the best kind of care." Without this document, all

From a life insurance standpoint, special-needs funding is more like planning for an estate than income replacement.

the other planning can be rendered meaningless--as the successor caregiver tries to relate to a stranger whose behaviors may be hard to understand.

Walther uses his brother as an example. "Sean loves golf," he says. "So from Thursday afternoon through Sunday, when a golf tournament is on TV, that is his time to watch golf. Don't screw with it, or you'll have a bad situation. He really likes certain kinds of foods, and detests other kinds of foods. All of those kinds of things, whether it is routines—and oftentimes with autism, there are very important routines that they follow—or all

the little idiosyncrasies, should be documented in detail, so that whoever takes over the care of your loved one knows the important things you know. They have a much smoother transition to that role, and provide the individual with exactly the care you would want her to have."

- 8) Allowing parents to themselves neglect in their efforts to provide for the specialneeds child. "Most families with a special-needs child end up in divorce," says Walther. "That's just the statistics. So I put the respite issue in my list of to-dos with the family. I tell them: you are going to schedule time for yourself to get away. You will tell me you cannot possibly do it, and I will tell you I don't care. You are going to find someone in the community, or a family member, who can stay with your kid for three or four days at a time. You can check in as much as you want, but you need to get away. This will become all-encompassing and all-burdensome if you don't, and that is not going to work for the relationship."
- 9) Forgetting the most important care issue as the family gets tangled up in the planning minutia. "I tell people: No matter what therapy treatments the doctors are doing with the kid, the most important thing you can do is hug and kiss your kid every day. It sounds corny," says Walther, "but if you look at the research, knowing they are loved is one of the most important things to advance their development. That is a huge thing, even though it is not technical."

#### Outsource Resource

Walther has hardly touched the small amount of food that he managed to forage from a breakfast spread that could easily have nourished an infantry battalion. He says that because the need is so great, and so few planners specialize in it, he's looking for ways to expand his firm, and become a more comprehensive resource for more advisors, perhaps an

outsource provider of specialized services that not everyone can easily master. He plans to charge for this advice, but is not yet sure how the revenue model would work. "It will probably be a virtual firm at first," he says.

Most advisors will want to refer to a specialist like him, but Walther says that for the few who jump into special-needs planning, the psychic rewards can be remarkable--far more satisfying than anything he felt when he was helping clients navigate investment markets.

"I never go home at night feeling bad," he says, touching abstemious portions of food musingly with his fork. "No matter what the market does, no matter what happens with client situations, I always feel good about what I did. This," he says, "was the greatest career change I could possibly have made."

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