BLUEPRINTS Planning for Special-Needs Families

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Independent, Individualized Investment Advice and Financial Planning

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Rob is the author of the following books:



Future planning – choosing between fear and courage

Last month, I spoke at the National Down Syndrome Society's adult conference in Detroit to a room of parents with adult children with Down syndrome. Some families were still figuring out how to navigate SSI, Medicaid and their estate plans but most had already accessed the government programs and taken steps to have a will with special-needs provisions included.

This was my first time in Detroit and the city was a pleasant surprise. My hotel was on the river and I could walk to the stadium where I saw the Tigers play the Royals. People were out enjoying the spring day and the city was active. For some reason, my image of Detroit was one of an abandoned city center with buildings in decay. My fear of walking around downtown quickly turned to enjoyment with so many people around enjoying their shopping, dining and opening weekend of baseball.

At the conference session and after, I talked with several people about the anxiety and fear that happens when they think about planning. They just cannot take steps forward or even think about the future. There are many reasons. They cannot imagine not being alive to care for their family member with a disability. They cannot see their family member living independently or with someone who can meet his or her needs. They cannot imagine how the family member will get to doctor's appointments, have friends or even have food and shelter.

The Blueprints process starts with a blank piece of paper and with you taking some time to write down what you want out of life – for you and for each member of your family. For our family members with disabilities, this means having the basics of food, health and housing. It means deciding what else our family member wants and what types of community involvement is expected – in the form of jobs, volunteer work, social life, education and entertainment.

Don't leave this paper blank as a result of a fear of the future. Take steps to overcome that fear and start planning. A good plan doesn't guarantee that the future will be perfect but it does get you started to protect benefits, improve your financial well-being, and helps you to live a more fulfilling and enjoyable life. Here are a few techniques to help.

Focus on the best qualities. One of my worries is that my daughter will be isolated. She loves school – not so much for the math, English and history as much as that she likes being in a social environment. She can walk the halls, see people and engage with teachers and students in her own way. It's active and lively. My memories of school are generally positive and I did well but I just remember sitting in class and watching the clock tick off seconds. She doesn't seem to have this problem. I've come to realize that she will find social engagement wherever she goes and my fears of her isolation, while possible, don't take into account the person she is today.

She finds ways to meet and interact with people. Of my three children, she is the one most likely to talk to strangers, find others to help her and make new friends quickly. When I think of this skill of hers, it helps me reframe what I expect from the future. Yes, I will have to find places for her to have these opportunities. Yes, she will need transportation. And yes, supporting who she is will make her life active, enjoyable and entertaining. As a parent, I feel like part of my job is letting my children find the best in themselves and then for me to encourage that quality of theirs. Some days it even works for everyone's benefit.

Engage supporting organizations. People want to help. There are organizations in your community dedicated to families like ours. So many people I've talked to only find these organizations when there's a crisis. They call the groups that specialize in school

Blueprints: Planning For Special-Needs Families Workshops

The **Blueprints** planning process was designed to help families with a member with special needs.

Workshops are free, but registration is required. More information at 719-632-0818 or online at ciginc.net.

Rob Wrubel is available for individual appointments.

Call 719-632-0818 to get started today.

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advocacy after a bad IEP meeting. They find the health group when there's hospitalization. A sibling finds a guardian agency only after the primary caregiver has a stroke. Why wait? These organizations, especially the ones focused on long-term care benefits funded through Medicaid, want to know you now. And you want to know them. Agencies do their best work when there's a relationship with the individual receiving benefits and, whenever possible, their families. The best organizations are as much about creating a second family as they are about the delivery of medications, food and support. You will be surprised at the sense of relief you feel when you find the right agencies to support your family - even if you won't need their support until many years down the road. It gives you time to understand what they can do and then to find alternative solutions for what they cannot.

Learn new skills. Sometimes we fear the future because we don't know if we have the right tools to excel. The future for our families often means receiving governmental benefits – and that comes with new reporting and advocacy skills to learn. There will be annual reporting so you might need to get organized and learn how to use Excel or Quicken.

and that could mean getting a lawyer and learning the new skill of working with competent professionals. We know that saving and investing for the future will relieve stress and anxiety and you might need to learn how to budget, save and stay out of debt

You can approach the need to learn new skills with fear, anger and worry but that won't help much. Or you can accept that these are life-learning opportunities and embrace them as they come.

There's a choice to make about planning for the future between fear and courage. Some days, it doesn't feel like a choice – we take what comes. There are moments of absolute anxiety about the future. Will Medicaid be cut? Will health issues improve? Will my family member be surrounded by people that care? We can sit around and worry about these issues or we can take steps to minimize them, plan for them and adapt as changes come. Live in fear or embrace today. You have a choice to make. I hope you choose courage and find ways to appreciate today while getting ready for whatever comes next.



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Rob Wrubel, CFP® AIF® AEP® is a Senior Vice President with Cascade Investment Group, member FINRA & SIPC. Rob is also a father of a daughter with Down syndrome. Cascade Investment Group is not a tax or legal advisor. You should always consult with your tax advisor or attorney before taking any actions that may have tax consequences. Call Rob at 719-632-0818 to schedule an appointment.