

IT'S YOUR TURN

Information to Help You Plan for Financial Success

Planning the Future for Children with Special Needs

DENVER, January 17, 2007 - When Karen Greenberg's son Ricky was diagnosed with autism back in 1990, she had two reactions. As a mother, she was determined to provide Ricky with the best possible care. As a CERTIFIED FINANCIAL PLANNER™ professional, she was determined to provide him with a lifetime of financial support as well, even after she herself had passed away. "In all my years of training and practice, I had never encountered this situation before," Greenberg recalls. "I realized I had no idea how to secure the future for my son, who would need financial help for the rest of his life."

Greenberg first turned for advice to an attorney. He suggested she disinherit Ricky and leave everything to her daughter, who would then have to assume responsibility for her brother's care. That didn't feel right to Greenberg; she didn't want her son's care to be her daughter's burden. So she immersed herself in the local law library to find a solution. She emerged with a comprehensive plan to establish a special needs trust, funded by a life insurance policy and savings, that would provide for Ricky while preserving his eligibility for government benefits like Medicaid and Supplemental Security Income (SSI). Then she did something else that combined her experience as a mother and a CERTIFIED FINANCIAL PLANNER™ professional: She set up Prosperity Life Planning, a non-profit organization that helps families of disabled children and adults in South Florida secure their loved ones' financial futures.

The disabilities that fall into the category of special needs are diverse, ranging from autism and Down Syndrome to mental illnesses and developmental delays. Yet special needs planning is still unfamiliar territory to many parents. In a survey carried out by [MetDESK®](#), the Division of Estate Planning for Special Kids at financial services provider MetLife, 60% of parents said they did not expect their special needs children to ever be financially independent. Yet 73% of parents had not yet begun setting aside money for these children. The [MetDESK®](#) Web site offers a [Special Needs Calculator](#) that can guide parents through the process of estimating a dependent's potential future income and expenses. There is also a page of [Resource Links](#) with tips on finding additional information about special needs issues.

Together with her husband Jaret Vogel, a financial services professional, Greenberg takes families with special needs children in South Florida through the entire financial planning process. An overview of that process can be found on the [Prosperity Life Planning](#) Web site. "I often ask parents, 'If you were to have died yesterday, what would you want for your family today?'" Vogel says. "Most families are hard-pressed. Caring for a disabled child costs more time and more money, so there is tremendous pressure on the family. It's hard to think 30 or 40 years ahead when you're struggling to cope and pay the bills right now. We're there to reassure families that this is not a black hole. We can help guide them through the process."



Ricky Rubin and his mother, Karen Greenberg, CFP®, of Prosperity Life Planning

A properly designed special needs trust can provide financial resources for the lifetime of a disabled child, even after the parents have passed away. The first step in creating one, according to the Prosperity Life Planning model, is writing a Letter of Intent. Parents are the best guides to their children's personalities and preferences, so Greenberg and Vogel encourage clients to think about how they would like their children to be cared for if they were no longer around. A Letter of Intent is not a legal document, but a sort of instruction manual. Greenberg and Vogel describe it as "a mini-biography of your child, a 'User's Guide' to explain the unique aspects of your child, his diagnosis, his level of functioning, and your vision for the future." They suggest that the letter be updated often and that other family members know its whereabouts.

The next step is to establish the child's legal guardians. "One of the things that most shocks people during workshops is that, when a child turns 18, the parents are no longer considered his or her legal guardians," Vogel says. "For disabled children, that means parents must apply for guardianship in order to make legal, personal or medical decisions for the adult child." When establishing guardianship,

Greenberg and Vogel advise parents to name alternates or successors who agree to serve as guardians in the event of their incapacity or death.

Once guardianship is arranged, it's time to name the trustee, the person in charge of the money in a special needs trust. A trustee can be a sibling, another family member or a friend. Some families are so small that it can be difficult to find someone to serve in this role. In that case, a bank or an attorney can serve as a trustee, for a fee that is normally a percentage of the total assets in the trust. It is also possible to select co-trustees, two people who work together – and must both agree – before any funds are paid out from the trust.

The final step is to set up the special needs trust itself, and to decide how to fund it. Trusts can be funded through savings, life insurance policies, investments, gifts and bequests. But anyone with more than \$2,000 in assets can be disqualified from government benefits like Medicaid and SSI. That's why it's crucial that disabled individuals are not named as beneficiaries in wills, life insurance policies or retirement accounts. This is also the primary advantage of a special needs trust: None of the money is considered as the assets of the disabled person, thus preserving that person's eligibility for federal benefits. There may also be significant tax savings to some families who use an Irrevocable Special Needs Trust to pay for certain qualified expenses.

Special needs trusts are complex, and laws on government benefits vary by state, so it's vital to enlist the help of a qualified attorney. Prosperity Life Planning, for example, works closely with a group of attorneys with an expertise in special needs planning. The [National Academy of Elder Law Attorneys](#), a non-profit association that assists lawyers specialized in disability legislation, is a useful resource for those seeking legal services for people with special needs and their families. "Most parents are not thinking about the long-term financial futures of their disabled children," Greenberg says. "And the ones that do think about it are often so afraid of making a mistake that they end up doing nothing." Greenberg's expertise and advocacy have taken the fear out of special needs planning, helping families with disabled children take action to secure their loved ones' financial futures.

Online Resources for Special Needs Planning

Planning a disabled child's financial future is a complex task. Here is a selection of some organizations that can help.

[Internet Resources for Special Children](#)

The Internet Resources for Special Children (IRSC) Web site is a central source of information for parents, family members, caregivers, friends, educators, and medical professionals caring for children with disabilities. The IRSC's online communities allow users to connect with other people to share questions, answers and experiences.

[Mental Health America](#)

Mental Health America works to improve the mental health of all Americans – especially the 54 million individuals with mental disorders – through advocacy, education, and research. The organization has more than 340 affiliates nationwide.

[National Academy of Elder Law Attorneys](#)

The National Academy of Elder Law Attorneys is a non-profit association that assists lawyers, bar organizations and others who work with older clients and their families. The Academy provides information, education, networking and assistance to those who deal with the many specialized issues involved with legal services to the elderly and people with special needs.

[National Alliance on Mental Illness](#)

The National Alliance on Mental Illness (NAMI) is dedicated to improving the lives of persons living with serious mental illness and their families. There are NAMI organizations in every state and in over 1,100 local communities across the country.

[National Dissemination Center for Children with Disabilities](#)

The National Dissemination Center for Children with Disabilities (NICHCY) serves as a central source of information on disabilities in children and youth. The NICHCY Web site has a list of [State Resources](#) with contact information for disability-related organizations in every state.

[Special Needs Alliance](#)

The Special Needs Alliance (SNA) is a national network of lawyers specialized in disability and public benefits law. Families can consult SNA to find the nearest lawyer with proven expertise in maintaining public benefits for disabled relatives as well as for estate planning to protect savings. The SNA Web site also has a section devoted to [Trusts for Disabled Children](#).