



## Ultimately, It's About Peace of Mind

Raising any child is a loving exercise in planning for the future.

Parents hope to maximize their children's potential for success and happiness. They provide their children with strength through love and support. They provide them with knowledge through education and exposure to varying experiences. They plan for their children to safely and successfully leave home and enter upon a fulfilling adulthood.

When you're the parent of a child with special needs, planning for the future takes on a more urgent and complicated meaning. Like all parents, you seek to maximize your child's potential for self-reliance, independence and the ability to enjoy life. *Unlike* other parents, you anticipate that your child may be dependent upon you for his or her home, standard of living, and social structure as an adult. Your concern for the future projects well beyond the age of adulthood. The uppermost question in the mind of every parent of a child with special needs is: What will happen to my child when I am gone?

Parents of children with special needs provide more than just financial support. They are their child's main advocates; they frequently provide their child's home and lifestyle during adulthood; they are the ones who know their child well, his unique likes and dislikes, and have learned through experience which approaches work with their child and which do not. That is why it is so critical for parents to create a specific, long-term plan for the future.

### COMPREHENSIVE SPECIAL NEEDS PLAN

Some considerations necessary to a comprehensive special needs plan are not immediately obvious:

*The human resources available through immediate and extended family, friends, and advisors (e.g., accountants, attorneys, ministers, therapists, doctors).* It is important to have an honest and complete understanding of what can be expected from these individuals.

*The values of the family.* A plan should consider the wishes of the family, and should endeavor to preserve what is important to its members.

*Disability support network.* Parents, as primary caregivers, companions, and advocates for their child, have developed a network support system through which they accomplish the daily tasks of living for and with their child. Governmental agencies, advocacy groups and other extended resources must be explored, and systems put in place for providing such things as social interactions, respite, vocational services, and referrals.

*The individual personality of the child.* Frequently the parents are the main repository of information concerning their child's likes and dislikes, needs and concerns. They also know in what manner they wish for their child's needs to be met, and how they prefer for him to be treated. Special needs planning must provide a mechanism for this information to be passed on to the caregivers who follow.

*Funding needs and resources.* It is important to calculate the actual costs the plan is intended to cover. While this cannot be exact, it can provide a guidepost for funding. There are many funding options for special needs planning, all of which depend upon the resources and choices of the family involved.

### LEGAL TOOLS

The basic tools of special needs planning are wills, special needs trusts, powers of attorney, guardianships, and letters of intent. Not all of these are applicable in all situations. Your attorney will guide and assist you in the choice of appropriate instruments for your plan. Two tools unique to special needs planning are:


*Special Needs Trusts.* SNTs are what most people think of when they consider special needs planning. They are trusts which are established following strict government guidelines that protect the individual's entitlement to government benefits. Families of children with special needs are aware that

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the government offers substantial, frequently irreplaceable benefits (i.e. medical coverage through Medicaid). However, the actual cash benefits are quite small and force the individual to live below poverty level. Special needs trusts, also called “supplemental trusts,” are a mechanism which allows you, the parents, to contribute supplementary benefits to your child.

**Letters of Intent.** A letter of intent is a document written by you, the parent, describing your child’s history, current status and what you hope for the future. You may write this letter today and update it year by year. While it is not a legal document, the court (and your appointed trustees or guardians) can turn to the letter for guidance. Your special needs planner may provide you with a worksheet to use in formulating your letter. This is something best started right away.

#### **PEACE OF MIND**

Special needs planning is more than just estate planning. For parents of children with disabilities, special needs planning answers the question, “Who will take care of our children when we are gone?” It is therefore meant to provide both a care plan and a financial plan, to address the issue of siblings and to forestall any conflicts, and ultimately, to provide peace of mind. It allows you to know you have done the very best you can to prepare for the future of your special needs children. 

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*The National Fragile X Foundation  
Presents  
Parent and Financial Planning Specialist*

**William Parker**  
**“Planning for Your Child’s Financial Future”**  
**Online - Audio Webcast**

Tuesday, April 26, 2005

6:00 p.m. Pacific ▪ 7:00 p.m. Mountain ▪ 8:00 p.m. Central ▪ 9:00 p.m. Eastern USA

William Parker is the father of five children, three of whom have fragile X syndrome. He has many years of estate and financial planning experience and is a certified estate planner and investment advisor.

He is a member of The National Fragile X Foundation’s Board of Directors.

Questions can be directed to Bill live by calling 1-800-218-0204 at the time of the event.

*(International participants please use email option below.)*

Email questions prior to the event to: [NATLFX@FragileX.org](mailto:NATLFX@FragileX.org) with a subject heading “For April 26 Webcast.”

The NFXF will do its best to see that everyone is able to participate, but regrets that it cannot guarantee that all calls and emails will receive an answer. *The foundation wishes to thank ACT Teleconferencing, Inc. for its support of this webcast.* To register for the free webcast in advance, or at the time of the event, visit: [www.actioncast.acttel.com](http://www.actioncast.acttel.com). **The Participant Login Event’s ID is: 27085.**