

Planning for Children with Special Needs

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Our special children with disabilities need our love, devotion, energy, compassion and patience. However, this is not enough. Their special needs also demand special planning. Parents of children with special needs know that their child will require lifetime care, care that can be both complex and expensive.

Parents also realize that there is a very good chance their special children may outlive them. Yet many parents have not planned for this eventuality. In many cases, parents have not even made wills! It is not surprising that many parents have not provided for the care of their special children when the parents can no longer care for them.

For the child with special needs, the consequences of failing to plan properly can be nothing short of disastrous. Many children with special needs cannot take care of themselves. They may be vulnerable. Who will care for the child? Where will the child live? Who will pay for the child's expenses? Who will administer necessary medication? Take the child to the doctor? Feed the child? You must plan for all aspects of care for your disabled child, and you should do it now.

Often, the parents are the only ones with the specific knowledge of the child's needs, medications, physicians, likes/dislikes, routines and habits. Absent proper planning, if you die suddenly, no one will know how to care for your special child. You must ensure that a transition will be as seamless as possible, to protect the special child from dislocation and disruption and assure a continuum of care and safety.

Many parents say they don't know where to begin. One excellent start is to



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take the following systematic approach: identify the special needs of your child; develop information about each need and a specific plan to address each need; and plan methods for paying the costs of meeting those needs.

In short, prepare a user-friendly road map, sometimes called a "Letter of Intent," containing as much information as possible on caring for the special child. Give the roadmap to the person who will care for your special child when you cannot. This way, whoever takes over as caregiver will have the necessary guidance and information to care for the child from the very first day.

Where to begin? First, visualize what the "letter of intent" or "roadmap" should look like. Imagine you are no longer around and someone has come to your

house in order to care for your special child. What would you tell that person if you could? Pretend you are writing a letter to the caregiver. At a minimum, your letter must address the following areas:

Medical / Physical - Specify in detail the nature of each of the child's disabilities. Provide a complete medical history starting from early childhood. If possible, list names and contact information for every doctor the child ever consulted. Identify current physicians and other care providers, medicines (with a schedule for dispensing them), pharmacies where the prescriptions are held. Provide addresses and telephone numbers. Specify the child's eating habits. What is her clothing size and taste. What kind of food does she like or dislike. Can she dress, feed, move, bathe or toilet herself. If not, what type of help does she need. Does the child have special transport needs.

Psychological / Emotional - Identify any psychological or emotional issues the child may have. Does he anger easily. Is he shy? If the child is receiving therapy, include details on the therapist and the type and frequency of treatments.

Safety - Is the child safe to leave alone. Are there any alterations to living arrangements that are currently necessitated by the disability or may become necessary if the disability worsens. What other steps must be taken by the caregiver to protect the child.

Social - What does the child like to do. Read. Watch TV. Play video games. Listen to music. Paint. Travel. Equally importantly, what does the child not like to do. If the child has friends, identify them, with addresses and telephone numbers.

Spiritual - Does the child have a faith life. Identify the spiritual counselor –

rabbi, minister, priest – with contact information. If the child does not have a spiritual counselor, consider establishing a relationship among yourselves, your child and a counselor. This will assure the child will have spiritual comfort upon your passing.

Economic - Will the child have money to live, to pay medical expenses. Where will the money come from – inheritance, government benefits. Does the child have a job. If so, where, and what are the work hours. Where will the child live. Is the child receiving any government benefits. If so, which ones. Provide details on the benefits, along with contact information at the relevant agencies. If the child is expected to inherit money from parents, grandparents or others, will the inheritance cause a loss of any government benefits that are based on financial need, such as Supplemental Security Income (SSI) or Medicaid. If so, have provisions been made for special needs trusts or other vehicles to receive the funds, instead of the child, in order to avoid losing those benefits.

As you engage in this process you will uncover areas that are as yet unaddressed.

Once you have completed your roadmap, review and update it regularly.

Some of the issues you must address are very complex, particularly areas involving financial planning, estate planning and government benefits. Avail yourself of the expertise of financial advisors, attorneys who deal with special needs issues, and other knowledgeable professionals. A simple mistake can have costly consequences.

The more complete your planning, the more information you can provide, the easier it will be for a caregiver to take over. Don't leave your special child exposed. Most of all, don't delay.