

Life Planning for Children & Adults with Special Needs

By Joseph Mastrangelo, brother of an adult sister with special needs, and parent of a child with special needs

As actors have roles in a play, parents of children and adults with special needs have their roles as well in “Life Planning” for their child. It’s a lifetime of various roles that have a direct effect on the daily and future quality of life of their children. As both a parent and a sibling of adults with special needs, I am quite familiar with the many roles I have played and continue to play. One of my most important roles is that of a “planner”. By putting together my daughter’s and sister’s “Life Plans”, I addressed their current and future personal, legal and financial needs.

Create a Personal Plan Diagnosis: Finding out and understanding your child’s diagnosis and needs are paramount in planning for your child’s current and future needs. My wife and I developed our own understanding of our daughter’s diagnosis which we use as a reference point for making decisions on treatments, therapies or medications. We also keep an open mind in assessing the options because we know that it is a life long process building on small incremental goals being reached over time.

Education Plan: During her school years, we found ways to work with the school system to meet many of her needs. We had our daughter evaluated and developed her Individual Education Plan (IEP). We established an amicable and supportive relationship with the educators through close communication. Any initiative or strategy whether at home or in school that had a positive effect or influence was communicated back and forth and supported by us and the school.

Social Plan: Concurrent with the IEP, we developed a Social Plan which was based on structured extra curricular activities and socialization. Activities for my daughter included a “Dog Biscuit” business and a “Jewelry” business as well as participation in Art programs. In order to address my daughter’s socialization needs, given her autism issues and her limited social skills, we installed a swimming pool which allowed us to provide a supportive environment by having her social network visit her. My sister’s, extra-curricular activities were therapeutic horseback riding and weekly dances organized through her day program. She attended an overnight camp during the summer and then moved into a group living situation which enabled her to blossom into an independent woman.

Shifting the Emotional Gears: As parents and caregivers, we came to a point when we mentally needed to move to a different level of acceptance with respect to our child and my sister. We saw our own denial as a kind of wishful thinking based on an expectation that they will out-grow their disabilities or get better. We found that this mind set

delayed our ability to make the difficult planning decisions. When we accepted that our family members will need long term support and care, we could move into an acceptance mode which allowed us to act, plan and implement strategies ensuring our their future quality of life.

Living in Parallel Time: As family members of individuals with specials needs, we live simultaneously in the present and future time frames. Given the constant concerns of the present, it may seem unfair that we are also concerned about the unknowns of the future with regard to the residence, care and quality of life of our child or sister. This is where making legal and financial plans, plays such an important role in addressing and alleviating these concerns and unknowns.

Your Child’s/Family Member’s Time Line: It is easy for parents and caregivers to get focused at particular points along your child’s life time line and lose sight of the overall picture. Whether its formulating and updating the “Individual

Education Plans” (ages 3-22), planning for transition to adult living, employment and/or post- secondary education, or applying for and securing “Public Benefits” at age 22-, parents still must be aware of the “Long Term” view. Many services, especially those outside the school system, are often outside our sphere of control and depend largely on the financial resources and political commitment of the state and federal governments for the care of your child.

When properly constructed and even modestly funded, creating a “Life Plan” can supplement these resources and enhance your family member’s quality of life

When should parents construct and fund their child’s long term Life Plan? Ask yourself what would happen to your child if you and your spouse were suddenly out of the picture. Where would your child live? Who would take care of them? How would they be financially supported? If there are no legal and financial plans in place, others or the state will be required to make all those decisions.

The first step is to make your own Personal Plan, then to start working with an Attorney and/or Financial Planner who are experienced working with families of children with special needs. They can assist you in developing the Legal and Financial Plans necessary to complete your child’s Life Plan. You will enjoy the peace of mind in knowing that the quality of life you expect for your child is securely in place for the rest of their life.

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