

## Life Long Planning For Families With a Member With Long Term Disabilities

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### NAVIGATING THE SCHOOL YEARS THE IMPORTANCE OF EARLY PLANNING

It is critical to make sure proper supports are in place for the child who may need life-long supports and services.

#### *When child is young or first diagnosed*

- Become familiar with the child's disability and medical needs - knowledge is power and understanding the child's disability as well as "abilities" is critical.
- Join support groups such as the National Association for Down Syndrome, The Arc, Epilepsy League, National Alliance for Mentally Ill, Tuberos Sclerosis Association, etc., to learn more about your child's handicapping condition and keep up with cutting edge treatments.
- Attend parent meetings, conferences, Special Ed advisory boards, list serves for parents, etc. Networking with other parents is helpful in accessing system (power in numbers).
- Recommend parents, grandparents, and other family members who may want to provide for the child with a disability to meet with a financial planner and special needs attorney to get basic estate planning documents in place, e.g., will, special needs trust, powers of attorney, etc. The Child may outgrow his/her need for assistance or Special Ed services but you want to be prepared for the worst if you die prematurely and unexpectedly. Grandparents can sign a power of attorney with a special Medicaid planning provision which protects assets for disabled grandchild if grandparent is in need of long term nursing home care.
- Remember to schedule time in for selves and other nondisabled family members.
- Remember the importance of 'scheduling in one's fun'.

#### *When child is in middle school and early teen years*

- Work with school and community groups (boy scouts, girl scouts, YMCA/YWCA, etc.) to assist child in learning proper social/behavioral skills to maximize integration with typical community.
- Continue attending parent meetings, conferences and the like to stay informed of opportunities that exist both in school and community based activities.

- Update your financial planning and estate planning needs to be sure your planning meets your current needs.
- Get information on SSI, Medicaid, Adult Rehabilitation Services, and other needed benefits (eligibility criteria vary from state to state). Consult with a disability attorney or elder law attorney to plan for your child meeting the requirements of these programs when s/he turns 18. There are look back periods for transfers of assets in every state so consulting with a specialist regarding transfer of asset rules is key to ensuring eligibility for these needs based programs when child turns age 18.
- Look into savings plans other family members may have provided such as U.S. Savings Bonds, 529 Plans, UGMA and UTMA accounts.

#### *When child is in the transition years 15-22*

- Begin investigating next steps for your child: options available beyond high school - what accommodations and supports will the student require if s/he goes on to graduate or technical schools after high school.
- Look into and apply for day programs and residential programs, if needed.
- Meet with Special Ed personnel at your child's school to identify academic skills (money management, basic reading, time telling, etc) or self help skills (personal hygiene skills, sex ed, meal preparation, housekeeping skills, etc.) the child will need to fend for him/herself beyond high school.
- Schools often want to stress self help skills in the last few years of high school when it appears college is not in the child's future. As high school is the child's only opportunity to learn academics, parents may need to balance the I.E.P. with the need to continue stressing academics along with the self help skills.
- Begin to investigate the differences between guardianship, limited guardianship, powers of attorney and other alternatives for advance directives so that by age 18, decisions can be made as to what appropriate action is needed so that family members can continue to advocate on behalf of adult disabled child.

- Meet with your financial planner and special needs attorney to update your estate plans, petition for guardianship if needed and/or draft powers of attorney for over age 18 children - all children not just special needs children.
- Discuss financial planning needs to preserve eligibility for SSI/Medicaid and other public benefits.
- Investigate applying for a Section 8 voucher to pay rent or using SSI payments to pay rent in the family home in order to maximize cash resources received each month. (Such planning can make it possible to afford the premiums associated with a survivorship or second to die life insurance policy which can provide critical dollars to fund a long term life care plan).
- Discuss steps grandparents and other well meaning relatives can take to ensure a secure future for family member with a long term disability.

### AGING OUT OF HIGH SCHOOL AND NAVIGATING THE MAZE OF ADULT SERVICES

It is important to have a life plan that enables the adult with a disability to receive needed supports and services in an appropriate setting.

#### *Developing a life-long plan is an ongoing plan:*

- Plan must be flexible to accommodate changing needs of person with a disability, his or her family as well as changes in public supports.
- Open a dialog with all involved (include the adult with a disability whenever possible as well as siblings, cousins, family friends and professionals such as attorney, financial planner, case worker, advocates, etc.).
- Research all public benefits that exist in community and respective eligibility requirements.

- Understand the difference between entitlement benefits and means tested benefits to preserve adult child's continued eligibility for critically needed benefits.
- Discuss financial eligibility requirements for needs based benefits with other family members who may leave disabled child an inheritance to be sure a well intended bequest does not result in a disqualification of needs based benefits.
- Identify and educate other family members or family friends who will advocate for the person with life-long disability throughout his/her lifetime.
- Important for siblings and other potential advocates to be familiar with individual's needs, wants, medical and social history.
- Important for siblings and other potential advocates to be familiar with government benefits, services, significant others in disabled individual's life, all the steps parents took to become familiar with their child's disability, best practices, how to advocate and navigate the system to best help their son or daughter should be repeated here for siblings and other potential advocates.
- It is important to write and keep a current letter of direction/intent.

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