



Lifelong Advocates for Marylanders with Developmental Disabilities ®

## LIFELONG PLANNING

***Advocacy for someone with a developmental disability is an ongoing process. What should I be doing at certain times in my child's life?***

### **From Age 0 to 21**

Your child is entitled to educational services that best meet his/her needs. An Individual Educational Plan is developed annually. Families may also apply for up to \$2000 from the Developmental Disability Administration's Low Intensity Support Services each July and January to address a specific support need/equipment/respite, etc.

Parents begin future and estate planning. Seminars are often available on topics such as:

Special Needs Trusts; How to Fund Trusts; Pooled Trusts

Guardianship Issues; Alternatives to Guardianship

Applying for services from the Developmental Disabilities Administration (DDA)

DDA Services for Adults: Vocational/Supported Employment, Residential/In Home Supports, Individual and Family controlled options through New Directions

How to apply for Social Security

Leisure and Vacation Programs; Community Integration Strategies

### **From Age 21 to 55**

The year your young adult completes school, he or she will have the opportunity to transition into a DDA funded day, vocational, or supported employment program. Although not an entitlement, the State Legislature historically funds services for transitioning youth each year. Note that this funding must be allocated by June 30 of the graduation year and once started, continues indefinitely. The federal government provides partial payment for most DDA services through Medical Assistance; it is important to assure Medical Assistance is maintained and renewed promptly as DDA may not fund services for those without MA. The Maryland service delivery system is intended to support self-determination, so that individual life choices are supported to the greatest extent possible. Once DDA services are funded, parents may attend the annual Individual Planning meeting to assist in developing a plan to address your relative's preferences and needs for the year.

If your service provider is unable to provide the service or you are dissatisfied, you may select a new service provider. DDA funding may be transferred to another provider. Your Resource Coordinator will assist you. You may also request a different Resource Coordinator/agency if necessary. Residential services are funded by DDA for those in urgent need, ie at serious risk of harm to self or others, pending homelessness, or living with a caregiver who is facing a crisis for example health issues resulting in an inability to continue to provide care. If you need services, ask your Resource Coordinator to update your situation and need for services with DDA. If a family in urgent need is denied funding for residential services, By Their Side can help identify comprehensive information to assist the State in reviewing the request again.

Parents begin to get their estate planning documents in order. If possible, a Special Needs Trust should be established to assure individual benefits and Medical Assistance are not interrupted while assuring available funds for uncovered healthcare/dental care expenses, preferred activities, and vacations. Pooled trusts allow smaller amounts

to be set aside for the benefit of a loved one without jeopardizing benefits. Once DDA residential services begin, benefits checks must cover room and board as well as a contribution to care, with some amount reserved for monthly personal use. Care is taken to assure assets do not exceed \$2000 so Medical Assistance is maintained. Pre-planned funeral arrangements can be made; Social Security provides guidelines. If the individual is his own guardian, a Medical Power of Attorney or Surrogate Decision Maker for medical issues can be named.

### **Age 55 and Above; The Senior Years**

At some point an individual in DDA services may wish to consider a slower pace of life and partially or fully retire from their typical day activity. DDA funding can be shifted into support of a “meaningful day” for example home based support with individualized outings combined with some days attending a senior center. Changing healthcare needs and risks associated with the aging process should be monitored. Assessments by a specialist such as geriatrician may be beneficial depending on the situation.

**By Their Side can assist through this lifelong process.**