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Quality of Care and Choices for People with Disabilities

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Persons with disabilities (PWD) often need care which may be outside the “norm” for others. Care needs may result from the type of disability that the person has. It is important to know the effects of a disabling condition on the daily life and capabilities of a beneficiary of a special needs trust (SNT).

While the parents and family members of the individual usually know and understand the impact of the conditions on the life of the PWD and their lives, the attorney working with them should become familiar with the symptoms and effects. An understanding of how the disability affects the beneficiary will enable the attorney to direct the individual or their caregivers to resources that will provide assistance and improve quality of life. Organizations that support persons with specific disabilities can offer assistance or connections to others who can provide helpful services and information.

LEARN TO FIND DISABILITY-SPECIFIC RESOURCES

Within the large number of persons with disabilities, there is great variation in the nature, scope and severity of disability conditions. Of course, disabilities are not alike. They are unique in their effects on each person affected – as well as their effects on the family members of the person with a disability. However, there are some general characteristics of certain types of disabilities. We will call these types Developmental Disabilities (“DD”), Traumatic Brain Injury-related disabilities (“TBI”) and Serious Mental Illness (“SMI”). An understanding of how and when such disabling conditions are generally acquired will enable you, and the client families you counsel, to anticipate a course of needs for the child or adult person with a disability. Once needs are anticipated, a course of solutions is easier to plot and resources are easier to put in place in advance of the need.

1. Developmental Disabilities

The U. S. Department of Health and Human Services Center for Disease Control and Prevention says of developmental disabilities: “Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and

usually last throughout a person’s lifetime.” About one in six children in the U.S. have one or more developmental disabilities or other developmental delays.¹

The CDC classifies developmental disabilities broadly as Autism Spectrum Disorders, Cerebral Palsy, Intellectual Disabilities, Hearing Loss and Vision Impairment. *Intellectual disability* is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation. Children with intellectual disability can and do learn new skills, but they develop more slowly than children with average intelligence and adaptive skills. There are different degrees of intellectual disability, ranging from mild to profound. A person's level of intellectual disability can be defined by their intelligence quotient (IQ), or by the types and amount of support he or she needs.

MedlinePlus defines developmental disabilities as follows: “Developmental disabilities are severe, long-term problems. They may be physical, such as blindness. They may affect mental ability, such as learning disorders. Or the problem can be both physical and mental, such as Down syndrome. The problems are usually life-long, and can affect everyday living. There are many causes of developmental disabilities, including:

- Genetic or chromosome abnormalities. These cause conditions such as Down syndrome and Rett syndrome.
- Prenatal exposure to substances. Drinking alcohol when pregnant can cause fetal alcohol spectrum disorders.
- Certain viral infections during pregnancy
- Preterm birth

Often there is no cure, but treatment can help the symptoms. Treatments include physical, speech, and occupational therapy. Special education classes and psychological counseling can also help.”²

¹ <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>, citing Developmental Disabilities: Delivery of Medical Care for Children and Adults. I. Leslie Rubin and Allen C. Crocker. Philadelphia, Pa, Lea & Febiger, 1989.

² <https://medlineplus.gov/developmentaldisabilities.html>

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