



Accept no one's definition of your life, but define yourself.
Harvey S. Firestone

Definitions of Acronyms and Terms

Advocacy is simply speaking out on issues that concern you or your family. This can mean something as formal as sitting down and talking to your legislator; as intensive as engaging in efforts to change laws or policies; or as simple as telling your neighbor about the impact of a policy or law on you.

Agency for Persons with Disabilities (APD) assists people who have developmental disabilities and their families. It also provides assistance to identify the needs of people with developmental disabilities and funding to purchase supports and services. Although the central office is in Tallahassee, the supports and services for people with developmental disabilities are provided through area offices throughout the state

Autism is a spectrum disorder with skills and deficits varying greatly from person to person. Autism is neurologically based and encompasses many areas of a person's life. It can cause difficulties in learning, verbal and nonverbal communication, and behavior. Typically, social interactions and imaginative abilities are also affected.

Cerebral Palsy (CP) is a group of disabling symptoms which results from damage to the developing brain. Cerebral means the brain and palsy means moving of the muscles in a way that the person can't control. This damage may occur before, during, or after birth and results in the loss or impairment of control over voluntary muscles. The motor disabilities caused by cerebral palsy do not get worse over time. Despite significant motor impairment, many people with CP have normal or above normal intelligence.

Circle of Support is the concept that positive family, peer, and community support is essential for people as they grow and develop, deal with choices and decisions, need to get and understand information, and need an extra hand living life or handling troubling or stressful times. Circles of support are normally made up of family members as natural supports; also, interested friends, extended family; peers, individuals associated with school and other educational activities, faith-based friends and groups, health care providers, and individuals in the community or established community support groups with which we participate.

Client means any person determined eligible by the agency for services.

Client advocate is a friend or relative of a client or of the client's immediate family. This person serves, who promotes the best interests of the client in any proceedings related to the APD in which the client or his or her family has the right or duty to participate.

Consumer Directed Care Plus Waiver is one of the waivers offered through the APD. This waiver allows participants to have more control and direction over the services provided.

Cost Plan is the approved budget for approved services provided to an individual served by the APD. The cost plan accompanies an individual's support plan and together are considered the plan of care.

Developmental disability (DD) is a broad term that refers to a variety of conditions that interfere with a person's ability to function in everyday activities. The disabilities identified by the Florida Legislature include: Autism, Cerebral Palsy, Cognitive Impairment (mental retardation), Prader-Willi syndrome and Spina Bifida. Most developmental disabilities are present at birth, but others may not be recognized and identified for several months or years.

Developmental Disabilities Institution is a state-owned and state-operated facility, formerly known as a "Sunland Center," providing for the care, habilitation, and rehabilitation of clients with developmental disabilities. These facilities are also known as DSI's and public ICF's.

Employment Initiative is a five-year plan that was designed to improve the availability of employment as an option for all people receiving APD services.

Enclave means a work station in public or private business or industry where a small group of persons with developmental disabilities is employed and receives training and support services or follow-along services among non-handicapped workers.

Epilepsy is a chronic brain disorder with various causes. It is characterized by recurrent seizures. When found with cognitive impairment, autism, or cerebral palsy, epilepsy is considered a secondary disability.

Express and informed consent means consent voluntarily given in writing. The person giving consent will have enough knowledge and understanding of the subject matter to make a clear decision without any element of force, fraud, deceit, duress, or other form of constraint or coercion.

Family and Supported Living Waiver provides services to adults with developmental disabilities who have goals to participate in their communities and may also have an independent living goal, as well. The FSL offers 11 services. The maximum total budget allowed in the FSL is \$14,282.

Family Care Council is an organized group of individuals who are appointed by the Governor. Their primary purposes are to provide information to individuals with developmental disabilities and their families and to report to the Agency area offices the needs of people served in their area. Members include people with developmental disabilities, their family members or guardians. There is one in each Area. Read more about them at <http://fccflorida.org/>

Family care program is one of the subsidies provided through the APD. It is funded with state money and has very limited availability.

Florida Freedom Initiative is a demonstration project that looks at what might happen if barriers are removed that keep people with disabilities from earning more money and becoming more self-sufficient.

Follow-along services are those services provided to persons in supported employment programs. They may include, but are not limited to, family support, assistance in meeting transportation and medical needs, employer intervention, performance evaluation, advocacy, replacement, retraining or promotional assistance, or other similar support services.

Foster home is a licensed residential facility which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. There can be no more than three residents living with the family who provides foster care.

Group home means a licensed residential facility which provides a family living environment including supervision and care necessary to meet the physical, emotional, and social needs of its residents. Group homes range in size from 4 to 15 residents.

Guardian is a person or a corporation who has been named by a court and has legal decision making authority over some or all areas or either a minor child's or an incapacitated adult's life. The authority given by the court will be explained in the Letters of Guardianship and may involve making personal decisions or his or her behalf, managing property or both.

Guardian advocate is a person appointed by a written order of the court to represent a person with developmental disabilities under 393.12 Florida Statutes.

Habilitation is the support provided to assist an individual with developmental disabilities to learn and keep life skills. These skills help the person to cope with his or her disability and environment. Habilitation includes but is not limited to programs of formal structured education and treatment.

High-risk child is a child from birth to 5 years of age with one or more of the following characteristics:

- (a) A developmental delay in cognition, language, or physical development.
- (b) A child surviving a catastrophic infectious or traumatic illness known to be associated with developmental delay, when funds are specifically appropriated.
- (c) A child with a parent or guardian with developmental disabilities who requires assistance in meeting the child's developmental needs.
- (d) A child who has a physical or genetic anomaly associated with developmental disability.

Home and Community Based Services Developmental Disabilities Waiver (HCBS DD waiver) allows people to receive services in a variety of locations in their community. This waiver offers 33 services.

In-home subsidies may be used to pay for basic living necessities like rent, utilities, food,

clothing, household supplies, or other household items, or for one-time moving expenses or start-up costs for establishing a household. These subsidies are available for people who live in their own home or family's home.

Intermediate Care Facility for the Developmentally Disabled (ICF/DD) is a 24-hour licensed residential facility for people with developmental disabilities. ICF/DD's provide for personal care, habilitation, developmental and intermittent, recurring medical care.

Internet, also known as the Web or World Wide Web, is a worldwide network of computer systems providing information through websites. APD has chosen to use the Internet as one way to provide training for consumers, providers, family members of persons with disabilities and other interested persons. Specific websites where training opportunities can be found are listed on the last page of this chapter.

Job coach is a person who provides employment-related training at a worksite to individuals with developmental disabilities.

Medical/dental services are those services that are provided or ordered for a client by a licensed person. Such services may include, but are not limited to, prescription drugs, specialized therapies, nursing supervision, hospitalization, dietary services, prosthetic devices, surgery, specialized equipment and supplies, adaptive equipment, and other services as required to prevent or alleviate a medical or dental condition.

Mobile work crew is a group of workers employed by an agency that provides services outside the agency, usually under service contracts.

Personal services include, but are not limited to, such services as: individual assistance with or supervision of essential activities of daily living for self-care, including ambulation, bathing, dressing, eating, grooming, and toileting, and other similar services that the agency may define by rule.

Prader-Willi syndrome is an inherited condition. A severe lack of muscle tone and failure to thrive are present in early infancy. Later on, an excessive drive to eat usually leads to significant weight problems. Obsessive-compulsive behaviors and difficulty with social interactions are often present. People with Prader-Willi syndrome are usually short with small hands and feet. They typically have mild cognitive impairment.

Residential facility is a place that provides room and board and personal care for persons with developmental disabilities.

Residential habilitation (Res. Hab.) means assistance provided with learning, keeping or improving skills related to activities of daily living (personal grooming and cleanliness, bed making and household chores, eating and the preparation of food), and the social and adaptive skills necessary to enable the individual to reside in a noninstitutional setting.

Residential habilitation center is a community residential facility that provides residential habilitation. There are at least nine residents in a residential habilitation center. After October

1, 1989, no new residential habilitation centers can be licensed and the licensed capacity can not be increased for any existing residential habilitation center.

Respite service is appropriate, short-term, temporary care that is provided to a person with developmental disabilities to meet the planned or emergency needs of the person or the family or other direct service provider.

Retardation is the term used in legislation to define one of the disabilities served by the APD. See Cognitive impairment.

Spina bifida means divided back bone or spine. When a person has spina bifida, the spine and the cord inside the spine do not grow the way most spines grow. Normally, the spinal cord carries messages from the brain to other parts of the body. When a person has spina bifida, the spinal cord does not carry all the messages to the rest of the body.

Support coordinator is a person who is designated by the agency to assist individuals and families in identifying their capacities, needs, and resources, as well as finding and gaining access to necessary supports and services; coordinating the delivery of supports and services; advocating on behalf of the individual and family; maintaining relevant records; and monitoring and evaluating the delivery of supports and services to determine the extent to which they meet the needs and expectations identified by the individual, family, and others who participated in the development of the support plan.

Support Plan is the document that identifies the needs and goals of an individual with developmental disability. It also identifies who will provide supports and services for the person. The support plan is effective for one year and can be updated whenever needed.

Supported employee is a person who requires and receives supported employment services in order to maintain community-based employment.

Supported employment means employment located or provided in a normal employment setting. Supported employment provides at least 20 hours employment per week in an integrated work setting. Earnings are paid on a commensurate wage basis. Continued support is needed for job maintenance.

Supported Independent Living Allowance (SILA) may be used to pay for basic living necessities like rent, utilities, food, clothing, household supplies, or other household items, or for one-time moving expenses or start-up costs for establishing a household. These subsidies are available for people who live in their own home or family's home.

Supported living means a category of individually determined services. They are designed and coordinated to provide ongoing supports for adults with developmental disabilities to live as independently as possible in their own homes. Supported living allows people to be integrated into the community and to participate in community life to the fullest extent possible.

Web is another term used to describe the Internet.

Web-based training opens opportunities for anyone who can get Internet access to learn more about a myriad of subjects. Websites for several training resources are listed on the last page of this chapter.

Web-based Training Resources

The convenience of online learning expands our access to information and can help us improve our capabilities. These organizations have provided opportunities for you to learn at home or anywhere you have access to the Internet.

Agency for Persons with Disabilities

Website: apd.myflorida.com (Click on the Clients and Families link at the top left and scroll down to the Online Training section at the bottom of the page.)

Delmarva Foundation

Website: www.dfmc-florida.org (Click on Enter the Public Site and then click on the Training Information link on the left side of the page. Click on Online Training and then click Registration Information to access the online training center.)

The Delmarva Foundation currently offers the following eight courses online.

- Preventive Health Care
- Protecting Consumer Rights
- How to Prepare for a Desk Review
- Recognizing & Reporting Abuse
- Introduction to Implementation Planning
- Results Focused Reviews
- Overviews of CORE and WISCC
- Why Do I Want a Medication Review?

Florida Developmental Disabilities Council

Website: www.fddc.org

On this website's home page, scroll down to the Health Care Transition Training Program section and click on the link (hctransitions.ichp.ufl.edu/ddcouncil/). This program provides five chapters on health care for youth (ages 14 to 21), who are transitioning from pediatricians to the adult medical world.