

Direct Care Core Competencies (DCCC) Course

Learner Guide – Module 2

This guide is designed for use with the
Direct Care Core Competencies Course



<http://apdcares.org/>

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Module 2: Introduction to Developmental Disabilities



Welcome to Module 2 – This module will introduce you to the knowledge, skills, and terms that will enable you to work effectively with people with developmental disabilities.

Module 2 Objectives

By the end of Module 2, you should be able to:

- Define the term developmental disability
- Name and describe the different types of developmental disabilities
- Learn the difference between developmental and functional disabilities
- Become familiar with the basic history of attitudes towards individuals with disabilities, and how it affects quality of life

What is a Developmental Disability?

A developmental disability is specifically defined in **Florida Statutes, Chapter 393.063(9)**, as “a disorder or syndrome that is attributable to an intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, or Prader-Willi syndrome; that manifests before the age of 18; and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.”

Another generally accepted definition of developmental disability is a diverse group of severe chronic conditions due to mental and/or physical impairments. Developmental disabilities can cause difficulties in certain areas of life, especially in language, mobility, learning, self-help, and independent living.

A condition is considered a developmental disability when it:

- Results in a significant mental or physical disability
- Occurs in the developmental years – before age 18
- Continues throughout a person's life
- Substantially affects the individual's ability to function, and
- Often means there is a need for some kind of assistance in daily living

Functioning

Functioning, or the ability to successfully get around in an environment, is a key element in defining a developmental disability.

Functional areas are usually grouped in the following way:

- Self-care
- Receptive and expressive language
- Learning, mobility
- Self-direction
- Independent living, and
- Economic self-sufficiency

Developmental Delay

A developmental delay is a very large difference between an individual's abilities and what is usually expected of people of the same age. This type of delay usually affects children from birth to 3 years old.

For example, it is common for babies to roll over at 4 to 6 months of age. An 8 month old baby who cannot yet roll over on his/her own, and cannot yet sit up without aid, raises concerns and should be tested for a developmental delay.

Developmental Disabilities

Florida Statute recognizes the following disabilities:

- Intellectual disability
- Autism
- Cerebral palsy
- Spina bifida
- Prader-Willi syndrome
- Down syndrome
- Phelan-McDermid syndrome

You will learn more about each of these disabilities in the upcoming slides.

Intellectual Disability

What is intellectual disability?

Intellectual disability is not a disease, it is a life-long condition with degrees of functioning (mild, moderate, severe, and profound) and varying levels of abilities.

People with an intellectual disability are likely to:

- Learn more slowly
- Have a hard time remembering things that are learned
- Have a hard time using what is learned, in a new situation, and
- Think about things in more real life or concrete ways

People with intellectual disabilities will keep learning and developing throughout life, like all of us.

Autism

What is autism?

Autism is a developmental disability that affects the brain areas controlling language, social interaction, and abstract thought. Little is known about the causes of autism.

Characteristics of autism may include:

- Avoidance of or not paying attention to others
- Difficulty relating to other people and communicating
- Monotonously repetitive motor behavior, such as rocking back and forth
- Repetitive behaviors that can cause injury to themselves
- Possible reduction in intelligence, and
- Behavior problems that include resistance to change and emotional responses

People with autism are usually sensitive to stimulation of their senses, sight, hearing, taste, touch, and can be overwhelmed by ordinary sights, sounds, smells, and touches.

The symptoms vary greatly, ranging from very limited disability to the lack of ability to speak or live independently. Autism is often not recognized or diagnosed until around the age of 18 months. It usually becomes apparent when a child fails to respond socially to family and friends.

Cerebral Palsy

What is cerebral palsy?

Cerebral palsy is a disorder of movement where people have difficulty controlling some of their body muscles. Each individual with cerebral palsy has very different kinds of abilities and challenges.

It is caused by damage to one or more specific areas of the brain, usually occurring before, during, or shortly following birth.

Other causes can include head injury usually resulting from a motor vehicle accident, a fall, child abuse, and/or a brain infection.

Some individuals with cerebral palsy may exhibit the following behaviors:

- Awkward or involuntary movements
- Poor balance
- Unusual walk
- Poor motor coordination, and
- Speech difficulties

It is important to know that cerebral palsy is not a disease or illness. It is not contagious, and it cannot be cured or grown out of.

Spina Bifida

What is spina bifida?

Spina bifida is a group of birth defects that affect the skin, spinal column, and spinal cord, in which the spinal cord fails to close. The causes are not known, but taking folic acid during pregnancy has been proven to dramatically decrease the risk of having a child with spina bifida (but it does not always prevent the disorder).

Spina bifida does not get worse over time. However, secondary problems can worsen and require intensive management.

Some of the health problems for people with spina bifida include:

- Not having a sense of touch or pain in the legs
- Having paralysis of their bladder or bowels that prevent them from controlling their bodily functions
- Possible curvature of the spine, and
- Pressure sores

The extent of these problems varies with the location of the defect along the spine and the effectiveness of early medical intervention. Some people with spina bifida have relatively few of the problems listed above. Others require on-going medical care in one or more specialized areas.

Spina bifida is one of the most common developmental disabilities of the nervous system. The incidence is about one in every thousand births.

Prader-Willi Syndrome

What is Prader-Willi syndrome?

Prader-Willi syndrome is an inherited condition. Although children and infants with Prader-Willi syndrome have similar features and symptoms, no one characteristic is specific to the condition.

Most people with Prader-Willi syndrome also have some degree of intellectual disability. Even when intelligence is at a typical level, some cognitive difficulties are usually present.

There are two distinct stages of Prader-Willi syndrome in the development of the child:

- Stage One occurs during infancy. Infants are often characterized as "floppy babies," and may result in feeding and swallowing difficulties.
- Stage Two occurs between the ages of one and two and is characterized by an obsession to eat and excessive weight gain.

Other characteristics of Prader-Willi syndrome include:

- Trouble pronouncing words
- Excessive sleepiness
- Decreased pain sensitivity
- Skin-picking habits, and
- Slowed growth

Personality difficulties may emerge between 3 and 5 years of age and include:

- Temper tantrums
- Stubbornness, and
- Acts of violence

Down Syndrome

What is Down syndrome?

Down syndrome is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. Another name used for Down syndrome is "Trisomy 21".

It is characterized by the following traits:

- Physical growth delays, and
- Mild to moderate intellectual disability

There are also common physical characteristics associated with Down syndrome:

- Low muscle tone
- Small stature
- Upward slant to eyes, and
- A single deep crease across the center of the palm

Phelan-McDermid Syndrome

Phelan-McDermid syndrome is defined as a disorder caused by the loss of the terminal segment of the long arm of chromosome twenty-two, typically leading to:

- Developmental delay
- Intellectual disability
- Dolichocephaly
- Hypotonia
- Absent or delayed speech

Functional Disabilities

There are other types of disabilities not identified and categorized specifically by APD, but may cause an individual to have difficulty with day-to-day functioning.

These are referred to as **functional disabilities**.

Some people you serve may have functional disabilities that arise from:

- Head injury
- Hearing loss
- Vision loss, and
- Epilepsy

You will learn more about each of these disabilities in the upcoming slides.

Head Injury

A head injury, also called a traumatic brain injury, is caused by an external blow to the head.

Some individuals will retain many of the skills they possessed prior to the injury. Others must regain a number of skills lost from the injury. The degree of impairment depends on

the extent and location of the injury.

The following is a list of symptoms that may result from a head injury:

- Somatic (headache, dizziness, poor coordination, weakness)
- Cognitive (amnesia, confusion)
- Emotional (agitation, depression)
- Psychosocial (fearfulness, impatience)
- Psychological (anxiety, guilt)

Individuals with a head injury may experience these difficulties, and possibly the emotional trauma of sudden changes in skills, sense of self, and role changes brought about by the injury.

If an individual acquires a traumatic brain injury before the age of 18 and manifests developmental problems, the **individual is considered to have a developmental disability**.

If the injury occurs at the age of 18 or later and results in a disability, it is **not** considered to be a developmental disability.

Hearing Loss

Hearing loss, or deafness, means a hearing impairment that is so severe, the individual has trouble processing spoken information.

Hard-of-hearing means that an individual has some loss of hearing.

The individual's age when a hearing loss is diagnosed is crucial to the development of the individual's speech, language, cognitive, and social skills. Treatment is most successful if the hearing loss is identified early.

Vision Loss

Vision loss, blindness, and partial sightedness, are terms that are legally defined. The legal definitions are based on an individual's degrees of visual acuity (clarity) and peripheral vision. When you look forward, peripheral vision is the range of vision on the sides of your vision.

Legal blindness means an individual has 20/200 vision, or less, in the better eye, with the best possible correction, and severely restricted side vision. 20/200 vision means an individual can recognize objects at a distance of 20 feet that an individual with normal vision can recognize at 200 feet. Only one in 1,000 people are legally blind.

Epilepsy

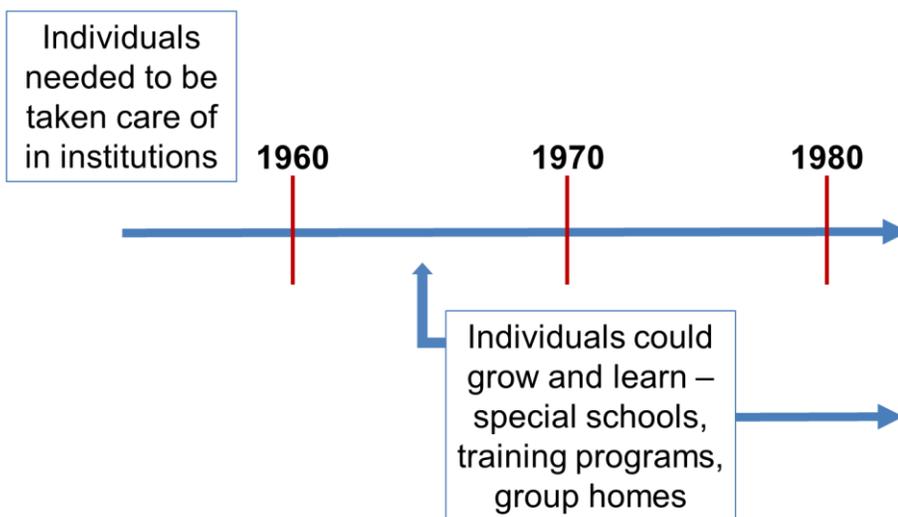
Epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works.

When brain cells are not working well, an individual may become unconscious, or their movement or actions may be very changed for a short time. These changes are called epileptic seizures. Epilepsy is sometimes called a seizure disorder.

Individuals who have epilepsy are able to function very capably in the community. Most people are able to reduce the frequency of seizures with proper medication and health practices. Some individuals with developmental disabilities may also have epilepsy.

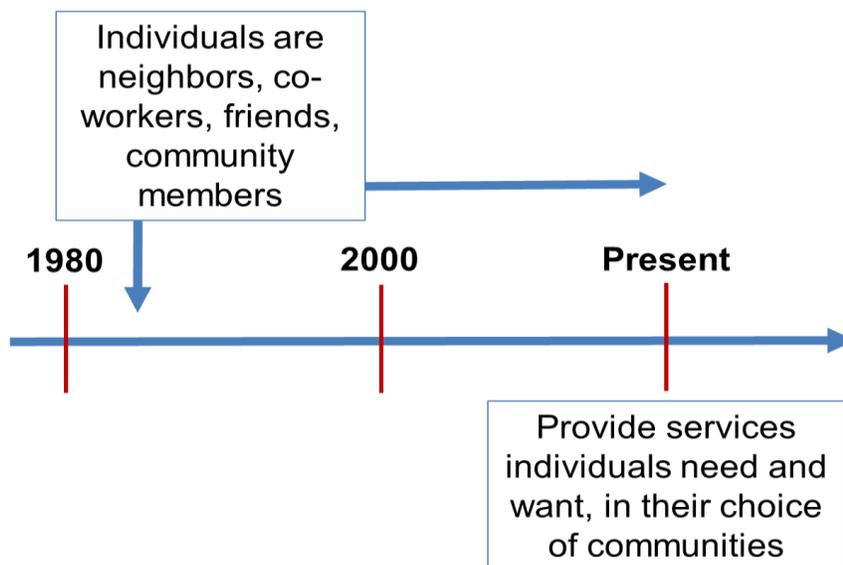
History of Attitudes

There have been major changes in how citizens in general have thought about people with developmental disabilities. These views have changed the way that services for individuals and families are provided, however, some people still hold onto old beliefs.



Up until the 1960s, citizens thought that individuals with developmental disabilities should be taken care of and that this could be best accomplished in an institution away from the community.

From the mid-1960s to the mid-1980s, citizens began to see that individuals with developmental disabilities could grow and learn through education and training. During these years, special schools, training programs, and group homes were developed in large numbers in communities throughout the United States.



From the mid-1980s to the present, citizens began to see individuals with developmental disabilities as their neighbors, co-workers, friends, and fellow community members.

Now, the focus is providing the services that individuals and families need and want in their choice of communities.

These changes in citizens' attitudes and in the way services are provided were largely due to the public education efforts of families of individuals with developmental disabilities. Changes in national and state laws along with individuals with developmental disabilities speaking up for themselves were also key to the current focus.

Quality of Life

You can help improve the quality of life for the individuals you serve.

As you go about your work in supporting people with developmental disabilities and promoting life quality for them, ask yourself these questions about each individual you serve:

- **Participation:**
Are there opportunities for participation in a variety of community and social activities? How can I help the individual to get involved in the activities?
- **Friendship:**
How many friends does the individual have? Would he or she like more? Are there opportunities to interact with and meet people?

- **Relationships:**

What opportunities do people have to be givers in a relationship? How are people recognized for their individual gifts and talents? How do I encourage interaction?

- **Interdependence:**

How are we supporting people to get connected within their communities? What types of natural supports exist in people's lives?

- **Independence:**

What skills are people learning? Are they able to have individual privacy, especially at home?

- **Meaningful Activities:**

Are people provided with purposeful activities in meaningful situations?

- **Motivation:**

Are people engaged in activities that are interesting and motivating to them? What can you do to increase the individual's motivation to participate in activities?

- **Choice:**

How much choice do people have throughout their day and throughout their lives?

- **Respect:**

How are people's routines and choices respected? How well do we listen to the people we support? How do we talk to the people we support?

Module 2 Review

Let's review some of what you have learned in this module.

What is part of the definition of a developmental disability?

A developmental disability occurs in the developmental years, before age 18.

Autism is often not recognized or diagnosed until around what age?

Often it is around 18 months old.

Spina bifida is a group of birth defects that affect the skin, spinal column and cord, in which what occurs?

The spinal cord fails to close.

And, Down syndrome is a genetic disorder caused by what?

It is caused by the presence of all, or part, of a third copy of Chromosome 21.

End of Module 2

Congratulations!

You have completed Module 2 of the Direct Care Core Competencies Course – Introduction to Developmental Disabilities.

You are now ready to start Module 3 – Maintaining Health, Safety, and Wellness.

We are just an email away!

If you cannot find the answer to your problem or require technical assistance, **please do not contact** the PFH technical assistance or FDOH; instead, contact the TRAIN Florida APD Support Team at apd.lmssupport@apdcares.org