

Chapter 2

Overview of

Developmental Disabilities

History of Developmental Disabilities

Throughout the history of mankind, cultural perspectives regarding individuals with developmental disabilities have caused them to be abandoned, cast out, abused, victimized and even killed. Whether this mistreatment was due to fear, hate or beliefs about spiritual, evolutionary or physical inferiority, society has always fought embracing them as equals and including them in the daily norms of life.

Recent history demonstrates the cultural reluctance that occurs even when in good faith, attempts are made to improve the acceptance and future of individuals with developmental disabilities. In the 1800's, a movement began where training schools were created to house the developmentally disabled and train them to be able to participate and function well within their communities. As their popularity grew, families were encouraged by doctors and other trusted advisors to place their children in these training schools. They believed that this was the best way for families to protect their developmentally disabled child from the mistreatment that they would otherwise receive at the hands of society. In the early 1900's however, the reasoning transitioned from protecting individuals from society, to protecting society from individuals. It became accepted and encouraged that placing a developmentally disabled child in a training school would protect marriages, siblings and even communities from potential harm. Between 1900 and 1925, the number of these "schools" grew in the United States from 10 to over 80. Small training schools became large institutions where the developmentally disabled were housed "out of sight" from daily life. With no oversight and the prevalence of ignorant perspectives regarding the developmentally disabled, horrific abuse became rampant and unchecked as the original intention of training was abandoned almost entirely.

A shift began again when, starting in the 1950's, parents began to take notice of worsening conditions. Working together, they demanded improved conditions and encouraged others to stop institutionalizing their disabled children. Appealing to the government for reform, their message took hold to change attitudes and inspire action. In the 1970's, significant legislative changes began to take shape providing for equal protection and opportunity under the law. The federal government began to require states to provide education and community services to families and individuals with developmental disabilities. In 2000, with the Developmental Disabilities Assistance and Bill of Rights Act, the federal government provided financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities.

Washington State definition of Developmental Disability

A disability attributable to:

- Intellectual Disability
- Cerebral Palsy
- Epilepsy
- Autism, or another neurological or other condition closely related to intellectual disability or that requires treatment similar to that required for individuals with intellectual disabilities, which:

Fundamentals

- Originated before the individual attained age eighteen;
- Continued or can be expected to continue indefinitely, and
- Results in substantial limitations to an individual's intellectual and/or adaptive functioning.”

Understanding Developmental Disabilities

Intellectual Disabilities

People with intellectual disability are individuals who have difficulty learning general knowledge as well as adaptive behavior. Adaptive behavior is the way an individual adjusts to the environment. When an individual has difficulty with adaptive behavior, he/she will also have difficulty meeting expectations for personal independence at his/her age level.

Characteristics and Considerations

- Learns more slowly, but with time and patience can often learn new skills and acquire knowledge to the same level as those without disabilities.
- Has a more difficult time remembering things that are learned
- Has a more difficult time transferring what is learned from one situation to a new situation
- Thinks about things in more concrete ways
- Keeps learning and developing throughout life just like anyone else
- There are different levels of intellectual disability from mild to moderate to severe; therefore individuals need different types of assistance in daily living.

Cerebral Palsy

While most with Cerebral Palsy have average or above average intelligence, they have difficulty with body movement due to damage to the brain.

Characteristics and Considerations

- May have limited control over their movements in one or more of the following ways:
 - ✓ Excessive muscle tightening
 - ✓ Awkward or involuntary movements
 - ✓ Poor balance and poor motor coordination
 - ✓ Speech difficulties
 - ✓ Tremors or shaking that occur while trying to perform coordinated movements
- Cerebral refers to the brain and Palsy to a condition that affects physical movement
- Ranges from mild to severe
- People can lead more independent lives through physical therapy and the use of adaptive devices (for example, computers and wheelchairs).

Epilepsy

People with a diagnosis of epilepsy or seizure disorder tend to have recurring seizures, usually resulting from a disorder of the central nervous system. A seizure is often described as an abrupt electrical storm, or eruption, that occurs in the brain.

Characteristics and Considerations

- Has seizures related to other health issues
- Can involve full body convulsions, brief partial movements, drop attacks, or lack of responsiveness (absence).
- Anything that the brain can do in its normal function, it can do abnormally in the form of a seizure.
- Frequently controlled by medications or VNS (Vagal Nerve Stimulus).
- Supports should be focused on safety and reassurance

Fundamentals

Autism Spectrum Disorder

Autism is a spectrum of closely-related disorders with a shared core of symptoms. The level of disability and the combination of symptoms varies tremendously from person to person.

Characteristics and Considerations

- Some of the most common symptoms include:
 - ✓ Problems with social skills
 - ✓ Difficulties with communication
 - ✓ Difficulties reading or exhibiting typical emotional responses
 - ✓ Repetitive and/or inflexible behaviors
 - ✓ Problems with sensory integration.
- The level of disability and the combination of symptoms varies tremendously from person to person. In fact, two people with the same diagnosis may look very different when it comes to their behaviors and abilities.
- Some helpful ways to help an individual with autism include:
 - ✓ Provide alternative forms of communication like sign language, PECS (Picture Exchange Communication System), communication software or electronic devices
 - ✓ Look for sensitivity to sounds, taste, touch and environment and adapt as appropriate
 - ✓ Follow routines based on person's preferences

Other Developmental Disabilities

People may have other neurological conditions closely related to intellectual disability that could also qualify as a developmental disability.

Characteristics and Considerations

- Includes people who need the same kinds of support as those who have intellectual disability.
- It does not include people who have only physical, learning, or mental health challenges.
- People with developmental disabilities may have both a diagnosis of the disability, and a mental health diagnosis, referred to as a "dual diagnosis" or "co-occurring diagnosis."

Principles of Normalization

- While everyone is unique, we are in many ways just as alike as we are different. We all have similar needs and wants. We all have the same rights. We all have feelings and can experience emotions such as love, loss, joy and embarrassment. We are all capable of learning and personal development. We all desire to make our own decisions for our life. We all desire to contribute. We all desire to be valued. This is no less true for the individuals we support.
- The Principles of Normalization seeks to pursue a life for the individuals we support that is respectful of the similarities we share. Normalization does not emphasize how people with disabilities are different from others. Our different backgrounds, values and perspectives sometimes conflict with another person's experiences. Often times, people mistakenly use their own standards as a yardstick for what is appropriate. This type of thinking reflects values that may not apply to others.
- Principles of Normalization stresses what people can do, rather than what they can't. It assumes that everyone can learn and has a need to grow. It places an emphasis on an individual's environment and the experiences they encounter. It understands that experiences can be planned which foster growth and learning. It is important to get to know the individuals you support to understand what is important to them and to assist them in living the life that they most desire.