SPECIALIZED FAMILY CARE
Provider Training

Category:	**Pre-Service Training**
Title:	**Developmental Disabilities**
Materials:	*Pre-service training handouts titled "Developmental Disabilities"*
Goal:	Applicant/Provider has a basic knowledge of developmental disabilities
Credit Hours:	1 Hour
Date Developed:	February 2010
Developed by:	Donna McCune, SFC Program

This skill-building instruction has been approved for Specialized Family Care Provider training by:

Teresa McCoy 8/15/2016

Specialized Family Care Program Manager **Date**

Carol Brewster 08-10-2016

Content Reviewed by: Carol Brewster, FBCS **Date**

Training Objectives:

- Specialized Family Care Provider can define a developmental disability, naming common examples
- Specialized Family Care Provider knows factors which may contribute to a developmental disability
- Specialized Family Care Provider knows how to honor the right of persons with disabilities to live as normal a life as possible

Training Procedures:

- Specialized Family Care Provider initiated self-study
- Test completed by Specialized Family Care Provider
- Review of test responses by Family Based Care Specialist and Specialized Family Care Provider

I certify that I have completed all the materials associated with this training module. I feel that I have a basic understanding of the material completed.

Specialized Family Care Provider **Start Time** **End Time** **Date**

Reviewed by:____

Family Based Care Specialist **Date**

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Pre-Service Training
DEVELOPMENTAL DISABILITIES

1. **HISTORY OF DEVELOPMENTAL DISABILITIES**
2. **OVERVIEW OF DEVELOPMENTAL DISABILITIES**
3. **NORMALIZATION**
4. **COMMUNICATION**

1. HISTORY OF DEVELOPMENTAL DISABILITIES

1950 –PRESENT ---THE BEGINNING OF COMMUNITY BASED SERVICES

The perception of persons with intellectual disability as developing citizens slowly began to gain acceptance in the 1950's. The resulting changes in the service system are far too complex and comprehensive to be covered in detail here. This section will provide a brief overview of two of the more important developments.

The Consumer Advocacy Movement

In 1950, a group of 44 delegates (largely parents) formed the National Association of Parents and Friends of Mentally Retarded Children. This group is now known as the National Association for Retarded Citizens (NARC). In 1983, its membership totaled more than 200,000 people in about 1,360 state local chapters. Local and state chapters, along with the national organization, have been involved in service program development, legislative and lobbying efforts and monitoring the service system.

The De-Institutionalization Mandate: The number of residents in state institutions reached a peak of nearly 20,000 in 1969. Since then, there has been a fairly steady decrease in the number of institutional beds in most states.

The general decrease in placements nationwide has resulted from the joint efforts of consumer advocates and the federal courts. Numerous lawsuits have been brought to improve institutional conditions and to facilitate the development of community alternatives.

In West Virginia today, there are no institutions for children or adults with intellectual disabilities and/or developmental disabilities.

History of Developmental Disabilities Services & Legislation

Legislation in the United States has been greatly influenced by the way persons with developmental disabilities have been perceived by society and the related philosophies that have developed regarding how these people (and/or society's other purposes) can best be served. This legislation has in turn largely shaped our service system into what it is today.

Services in West Virginia have in general followed national trends. However, recent legislation and court cases have created large and important changes in West Virginia's service system for persons with developmental disabilities. These changes are creating exciting choices and opportunities for persons with developmental disabilities and the people who serve them.

It is important to understand the history of services for persons with developmental disabilities to understand why these services are the way they are today. Similarly, recent principals, philosophies and service trends continue to greatly influence the continuing evaluation of this service system at all levels, from individual agencies all the way up to the federal government.

For paraprofessionals, this information will provide them with the background needed to understand the role of the agency they work in. Similarly, for the paraprofessional to provide optimal services to persons with development disabilities, they must have a clear understanding of the issues which continue to shape this system.

Beginning with the Thirteenth Amendment to the U.S. Constitution, laws have been created to support the basic rights of Americans. In the 1960s, John Kennedy (who had a sister with intellectual disability) convened the President's Committee on Mental Retardation. This group looked at how people with disabilities had been treated and the basic rights often denied them. In the 60's, legislation was developed which provided funding for research centers, training programs dealing with disabilities, and established health services for mothers and children.

In the 70's, the first Developmental Disabilities Act provided core support in the areas of education, employment, treatment and advocacy and prohibited discrimination. Legislation also established a Developmental Disabilities Planning Council and a Protection and Advocacy System for each state and gave funding for University Affiliated Programs around the country. The Education of all Handicapped Children Act

(1975 and 1986) provides interagency early intervention programs and mandated free education in the least restrictive environment for children ages 3 to 23.

This means that all children, no matter what disabilities they have, have the right to an appropriate education in our public system, which gives them the services they need to learn and grow while allowing for the maximum integration (Public Law 99-457).

The Developmental Disabilities Act of 1984 and 1988 (Public Law 100-146) state that individuals with developmental disabilities have the right to independence (living, as much as possible, on their own) productivity (learning and working) and community integration (living in communities in the least restrictive, family-oriented setting). Other legislation financially supports individuals with developmental disabilities to pursue these rights.

Aside from federal legislation, West Virginia has two additional Class Action lawsuits which mandate certain rights and services.

Medley

In 1981, the first Class Action Lawsuit, Macel Medley vs. Department of Human Services, Health & Education or "Medley" resulted in the first interagency planning team for this population which resulted in a statewide systems for foster care and guaranteed all "Medley" class members individual program plans (IPP) developed by interdisciplinary teams (IDT). Provisions were made in the decree for continuing funding for services for Medley Class Members.

Medley Class Members

- Under age 22
- Intellectual Disability - IQ below 70
- WV Residents
- Resided in institutions after 4/1/1979 for 30 days

Hartley

In 1983, a Class Action Lawsuit, E.H., et al, vs. Khan Matin et al or "Hartley" set forth a system and sequential program for improving the delivery of mental health services, intellectual disability services and services for alcohol and drug abusers.

Hartley Class Members

- All children and adults who have resided in state institutions or who are at risk of institutionalization.

The Decree outlined a continuum of care which included a variety of institutional and non-institutional living arrangements, treatment based on individual needs, normalization of living conditions, treatment in the least restrictive setting possible and assurance that clients have access to advocacy.

2. OVERVIEW OF DEVELOPMENTAL DISABILITIES

People with developmental disabilities are, first and foremost, **people with abilities**. Without special assistance some people with developmental disabilities cannot take advantage of the freedoms and opportunities of our society. They are, however, more like the rest of the population than they are different. People with developmental disabilities have special needs, but their basic needs are the same. Funding, policies and services often have been focused only at the special needs of people with developmental disabilities.

A developmental disability is a severe, chronic disability which:

- Is attributable to a mental or physical impairment or a combination of the two
- Is manifested before the person attains age twenty-two
- Is likely to continue indefinitely
- Results in substantial functional limitations in three or more of the following areas of major life activity:
    1. self-care
    2. receptive and expressive language
    3. learning
    4. mobility
    5. self-direction
    6. capacity for independent living
    7. economic self sufficiency
- Reflects the person’s need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are lifelong or extended duration and are individually planned and coordinated.

We have learned that services are most successful when basic needs are met in the context of addressing special needs. People with developmental disabilities, like all people, need:

- To be seen, first of all, as people
- To experience love and friendship
- To experience continuity in their lives, especially in relation to the people who are important to them
- To be respected and treated with dignity
- To have access to opportunities and information, to make choices and to exercise their rights
- To learn those skills which are needed to participate as valued members of their community
- To have a decent and appropriate place to live
- To have meaningful employment and contribute to the community
- To have opportunities to continue to learn throughout their lives

In response to these basic needs, our hopes for the future and our thoughts about the quality of our lives are often concerned with three basic issues – HAVING A HOME, not just a roof over our heads; LEARNING skills which are useful to our lives and careers, not just going to school; and WORKING, not just keeping busy. There is a fourth basic issue which gives vitality and fullness to our lives – DEVELOPING AND SUSTAINING RELATIONSHIPS with people who depend on us and upon whom we can depend.

A real home is a place to live the most personal moments of our lives. A home provides security and comfort, allows us to make choices and express ourselves. The people who share our homes are usually the people with whom we choose to spend time, be ourselves and feel close.

Real learning is life long. It means learning to understand ourselves. Learning involves developing skills which are useful to us both as individuals and as members of communities. The people with whom we learn are also teachers. Many become friends we can count on throughout our lives.

Having a home, learning and working – each involves us as members of a community who receive the support of others and make contributions to the community. Each involves us in the continuing process of individual expression. Each involves us in developing relationships.

Having a real friend means being involved with someone who chooses to spend time with you just because they want to and not because they are paid to do so. Real friends broaden our opportunities and enrich our lives. Real friends are hard to find. It takes most of us a long time through contact with many different people to find that small group of friends who really matter. Opportunities that lead to friendships are essential.

People with developmental disabilities often are more handicapped by the environment than by their disabilities. Historically, our thinking and actions have focused on the inabilities of people with developmental disabilities. The concern was with “fixing the person” or “curing the deficit.” Over time, that focus has shifted to building on capabilities and assisting individuals to develop and use their abilities.

The most dramatic shift in our way of thinking is the recognition that the social and physical environments are often a greater issue than abilities and disabilities. This is especially true in considering the expectations others have of people with developmental disabilities, and what people do based on those expectations. Many people believe that a “disability” and a “handicap” are the same thing. We have already noted that a disability is a physical or mental condition that limits a person’s ability to do something independently. According to the dictionary, the definition of the word “handicap” is “any disadvantage that makes achievement or success difficult.” While the word “handicap” has long been used as a synonym for “disability”, this usage is inappropriate. Persons with a disability may have physical or mental limitations, but they do not necessarily have a handicap unless it is imposed on them by our society. For example, a person with paraplegia (paralysis from the waist down) who uses a wheelchair has a disability but is only handicapped when the lack of a ramp prevents her from entering a theater. Similarly, a child who has intellectual disability is handicapped by classmates who call him names and do not include him in their activities.

Causes Resulting In Developmental Disabilities

When the developmental process veers off course or stops, it may be due to factors within the body such as inherited genetic influences, or due to factors outside the body such as environmental influences. In some cases it is due to a combination of genetic and environmental factors:

Genetically - We know that many conditions can be passed on from one generation to the next. A host of chromosomal and metabolic disorders resulting in alteration of brain structure and function are attributable to genetic factors. Example: Down Syndrome

Environmentally - Many things happen to the development process as a result of external forces. These influences can be beneficial – such as excellent nutrition, good health, or good schools which enhance development; or they can be detrimental such as malnutrition, head trauma, or infection which may inhibit development. The effect depends not only on the nature of the environmental factors, but also on the stage of the individual's neurological development. Example: lead paint poisoning

Prenatal – Before birth problems can be devastating since they interfere with the actual structural development of the brain and organ systems. Example: German Measles (Rubella)

Maternal Disease Conditions

- Chronic renal disease
- Diabetes
- Toxemia
- Rh incompatibility (mother Rh negative and fetus Rh positive)
- Poor nutrition

Direct Damage to Fetus

- Infection, i.e., Rubella (German Measles), syphilis, AIDS
- Radiation
- Drugs and chemicals
- Genetic defects, i.e., Down Syndrome
- Metabolic (chemical) errors or inborn error in metabolism

Perinatal – Birth problems occurring around the time of labor and delivery may interfere with the proper transport of oxygen and other nutrients to the brain. The process of birth is the single major challenge to the newborn. Example: Cerebral Palsy

Maturity

- Premature less than 37 weeks
- Postmature
- Low birth weight less than 2K grams (4.5 lbs.)
- High birth weight – greater than 4.5K grams (10 lbs.)

Labor and Delivery

- Prolonged or severely irregular contractions will interfere with blood flow in fetus

Presentation of Fetus

- Breech – rump or feet first
- Transverse – long axis of body is at right angle to the birth canal.

Analgesia and Anesthesia (drugs)

Multiple Births

Postnatal – After birth problems are those occurring after the newborn period. These may include environmental causes. Examples: head trauma and malnutrition

Physical Trauma

- Accidents
- Child Abuse

Disease (brain damage or weakened organs)

- Infections
- Meningitis
- Encephalitis
- Influenza
- Tumors

Drugs and Chemicals (i.e., lead poisoning, babies born addicted to cocaine, etc.)

Nutrition

- Malnutrition
- Diets high in certain nutrients

TYPES OF DEVELOPMENTAL DISABILITIES

While there are over 200 kinds of developmental disabilities, this lesson will mention some of the more common ones. These include specific learning disabilities, epilepsy, blindness/visual impairments, intellectual disability, pervasive developmental disorders, orthopedic disabilities and Fetal Alcohol Syndrome. It should be noted, and will become apparent, that some of these disabilities, in and of themselves, do not meet the criteria for classification as a developmental disability when they are not severe or do not co-occur with other disabilities. Others, however, are almost always developmental disabilities.

Specific Learning Disabilities

Specific learning disorder is now a single, overall diagnosis, incorporating deficits that impact academic achievement. Rather than limiting learning disorders to diagnoses particular to reading, mathematics and written expression, the criteria describe shortcomings in general academic skills and provide detailed specifiers for the areas of reading, mathematics, and written expression.

Characteristics of Specific Learning Disorder

Specific learning disorder is diagnosed through a clinical review of the individual’s developmental, medical, educational, and family history, reports of test scores and teacher observations, and response to academic interventions. The diagnosis requires persistent difficulties in reading, writing, arithmetic, or mathematical reasoning skills during formal years of schooling. Symptoms may include inaccurate or slow and effortful reading, poor written expression that lacks clarity, difficulties remembering number facts, or inaccurate mathematical reasoning.

Current academic skills must be well below the average range of scores in culturally and linguistically appropriate tests of reading, writing, or mathematics. The individual’s difficulties must not be better explained by developmental, neurological, sensory (vision or hearing), or motor disorders and must significantly interfere with academic achievement, occupational performance, or activities of daily living.

Epilepsy

Epilepsy is a disorder of the central nervous system that results in episodes called seizures. (Other, colloquial, terms for seizures include spells, fits, attacks, and convulsions.) Seizures occur when there is a temporary increase in the electrical impulses present in the brain. This causes the brain to lose control over consciousness and unconsciousness and over various parts of the body. Epilepsy can be caused by an injury to the brain by accident, illness, lack of oxygen or can accompany other disabilities, such as cerebral palsy or intellectual disability. Not all persons with epilepsy, however, have developmental disabilities, as onset of epilepsy may occur at any age, and since control of seizures through medication may preclude development of other disabling conditions.

General types of seizures are:

1. Petit mal: More common in children than adults. These seizures consist of brief periods of unawareness with few other signs. Typically, the person stares blankly. Petit mal seizures in children are often mistaken for daydreaming.

2. Jacksonian: Characterized by uncontrollable movements like shaking and jerking. The activity is typically confined to one area of the body (e.g., to one side of the body). The person does not lose consciousness, but simply cannot control this activity.

3. Psychomotor seizure: Characterized by seemingly erratic behavior. That is, the person stops what she/he is doing, stares blankly, and then engages in some purposeful behavior (e.g., lip smacking, buttoning and unbuttoning). The person cannot control this activity. The seizure has duration of about 1 to 2 minutes, and is followed by a return to normal consciousness.

4. Grand mal: The most common type of seizure, grand mal seizures are characterized by convulsive movement (stiffening and jerking of the body) and loss of consciousness. The person typically falls to the floor and the seizure continues for a relatively brief time (usually 2 to 5 minutes). Breathing may be shallow, excessive saliva may accumulate, and bladder control may be lost.

Blindness/Visual Impairments

Visual impairments can range from very mild to very severe. It has been estimated that as many as one fourth of school-age children have some visual problem. Most of these problems are corrected by glasses or contact lenses.

Normal eyesight is referred to as 20/20. This means what the person sees from 20 feet is what others can also see from 20 feet. Visual impairment begins at 20/70. With this degree of impairment, a person cannot see well enough to drive a car. The point at which one is classified as legally blind is 20/200. A person with this degree of impairment would have to stand as close as 20 feet to see an object that could be seen by someone with normal vision at 200 feet away.

Visual impairment can take several forms. A person's vision may be fuzzy or may be completely clear but limited to what is immediately in front of him in a narrow band (tunnel vision). Many people who are legally blind can read large or even ordinary print. Other persons who are legally blind can distinguish objects well enough to move around unaided and most are able to distinguish light from dark. Very few persons are actually completely blind.

Deafness/Hearing Impairments

Hearing impairments are one of the most common disabilities. One out of every ten persons has some degree of hearing loss. As was the case with visual impairments, hearing impairments can have many causes. Persons can be born with abnormalities in the outer or inner ear or auditory nerve. Hearing impairments can occur at any time of life as a result of various illnesses or injuries, as well as a general wearing out of the bones of the middle ear with aging.

There are two types of deafness:

1. Conductive deafness occurs when sound waves cannot be transmitted in the outer or middle ear. There may be a blockage, a foreign object, or other interferences with the normal movement of both bones of the middle ear. The main problem with conductive hearing loss is a lack of auditory acuity or keenness. Conductive hearing losses can often be helped with surgery or with the use of sound amplifying hearing aids.

2. Sensorineural hearing impairment is caused by damage or abnormalities in the inner ear or auditory nerve. The result is that sound may be received at a lower volume, or is distorted. Sensorineural hearing impairment can be caused by complications of infectious diseases, lack of oxygen during birth, maternal exposure to rubella during the first three months of pregnancy, or prolonged exposure to excessive noise. This type of hearing loss is presently not correctable through surgery or medication. Certain types of sensorineural hearing impairments can be aided by sound amplification with hearing aids, although some types of hearing aids function only to amplify already distorted sounds to unbearable levels.

Intellectual Disability

The American Association on Mental Deficiency (AMD) defines intellectual disability as "significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period." Significantly sub-average intelligence refers to a score of two or more deviations below average (i.e., average =IQ score of 100) on a standardized intelligence test. Persons with IQ scores of less than 70 would be considered as having sub-average intelligence. Intellectual Disability refers to a level of performance without reference to etiology. More importantly, being labeled as intellectually disabled does not imply a forecast for motivation, treatment, and possible training opportunities. It simply means that persons who have an intellectual disability function below what is considered average or normal. Adaptive behavior refers to the degree of effectiveness with which an individual meets the standards of personal independence and social responsibility expected for his/her age and cultural group. General types of adaptive behavior are: sensory motor skills; communication skills; self-help skills; and social skills. Additionally during childhood and early adolescence, deficits may be found in such areas as basic academic skills, abstract thinking, and judgment in daily experiences and interpersonal relationships.

Only some of the causes of intellectual disability can be identified. Typically disease, injury, or a genetic problem occurs and affects the brain during conception, pregnancy, or during birth. Poverty and its effects (poor nutrition, unsanitary conditions, lack of prenatal care, poor housing, and physical, intellectual, and emotional deprivation) can also result in an intellectual disability. Intellectual disability can range from mild to moderate, severe, and profound. The persons in each level share common characteristics and are approached differently in the areas of treatment and education. Persons with a mild intellectual disability make up about 80% of all persons with an intellectual disability with their abilities being just below the low end of normal range. There are very few differences between these persons and their peers who do not have an intellectual disability. Persons with a mild intellectual disability can and do learn in the academic areas – they simply learn at a slower rate.

Persons with a moderate intellectual disability often show generally delayed behavioral development, as well as deficits in intellectual behavior. That is, they acquire skills such as sitting up, walking, and talking at a slower rate than their peers without an intellectual disability. Persons with a moderate intellectual disability can learn, although most of their academic training tends to center on vocational or job related skills, and personal, social, and self-help skills.

Persons with severe and profound intellectual disability often have other disabilities, such as visual or hearing impairments, cerebral palsy, epilepsy, or serious orthopedic handicaps. These individuals may require much assistance and extensive training to care for their basic needs. Lack of appropriate training often brings about quite complex patterns of verbal (but non-spoken) behavior in individuals with this level of intellectual disability and frequently results in development of self-stimulatory or stereotypical patterns of behavior.

One fairly common type of intellectual disability is Down syndrome. This condition is caused by the presence of extra genetic material and cause both physical differences and mental retardation. Persons with Down Syndrome can have intellectual ability that ranges from near normal to profound intellectual disability, although usually the degree of the disability is mild to moderate. Physical differences can include slanted eyes, a small nose, a short heavy build and heart abnormalities.

Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is now defined by the American Psychiatric Association Diagnosis and Statistical Manual of Mental Disorders (DSM-5) as a single disorder that includes disorders that were previously considered separate – autism, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder (PPD) not otherwise specified.

Autism Spectrum Disorder (ASD) is a serious neurodevelopmental disorder that impairs a child's ability to communicate and interact with others. It also includes restricted repetitive behaviors, interests and activities. These issues can cause significant impairment in occupational, social and other area of functioning.

The number of children with ASD is on the rise. It is not clear if this is because of better detection or an increase in the number of cases. There is no cure for ASD but early treatment can make a difference.

ASD is developmental disabilities which result in impairments in social interactions, communication and behavior. Social interactions impairment may be: failure to respond to his/her name or appears not to hear at times, resistance to cuddling, hugging, or holding and retreats into their own world, doesn't talk or has delayed speech, speaks with abnormal tone, repeats works or phrases, etc. Behavior impairments may be: performs repetitive movements such as rocking, spinning or hand-flapping, may be uncooperative or resistant to change, has problems with coordination or movement, etc.

Most children with ASD have signs of lower than normal intelligence, while others may have normal to high intelligence. Children with ASD usually show signs of delayed development within the first year. Children with the least severe problems, eventually may lead normal or near-normal lives. ASD may occur in all racial, ethnic, and socioeconomic groups. ASD is four times more likely to occur in boys than girls, with the exception of Rett Syndrome, which occurs almost exclusively in girls. Children with certain medical conditions such as fragile X syndrome, tuberous sclerosis, Tourette's syndrome, or Rett syndrome are at a higher risk to acquire ASD.

While we have learned a lot about symptoms, we still know little about the cause of these disorders. Scientists think that both genes and the environment play a role, and concede there may be many causes that lead to these disorders. Genetic known causes may be a fragile X syndrome or Rett syndrome.

Orthopedic Disabilities

Orthopedic disability is a general term that refers to a physical condition that causes problems with gross and/or fine motor capability. Gross motor activities include walking sitting, standing, and crawling, while fine motor activities include such things as writing, drawing, cutting with scissors, or picking up buttons or coins.

There are many different kinds of orthopedic disabilities. These include cerebral palsy, arthritis, spinal cord injuries and muscular dystrophy. Orthopedic disabilities are usually quite visible because of the presence of aids such as wheelchairs, crutches, walkers, or by uncontrolled or unusual movement.

There are many different causes of orthopedic disabilities. They can be caused by brain injury before or during birth as is the case with cerebral palsy, by an illness or injury to the spinal cord, or by an inherited or genetic problem, as is the case with muscular dystrophy. These disabilities can also differ in other ways. For example, problems in movement can range from minor stiffness in some joints to complete body paralysis. Orthopedic disabilities can also be of a progressive or non-progressive nature.

Examples of Orthopedic Disabilities:

- Cerebral palsy is a non-progressive disorder typically caused by problems during pregnancy or during the birth process, such as anoxia, viral infections, lead poisoning, or Rh incompatibility. These problems cause injury to the portion of the brain that controls voluntary movement and muscle activity. Two types of cerebral palsy are spastic cerebral palsy, which causes tight muscles that move very stiffly and only with great effort, and athetoid cerebral palsy, which causes excessive, uncontrolled and involuntary movement. Persons with cerebral palsy often have other problems as well, such as speech impairments or epilepsy. Treatment usually covers many areas of therapy and rehabilitation.

- Muscular dystrophy is a progressive orthopedic disorder. It is most commonly a hereditary disorder although it can occur spontaneously. It causes progressive muscle weakness that eventually becomes so pronounced that the person must use a wheelchair or is confined to bed. The most common type is eventually fatal, usually within ten to fifteen years, while other forms of the disability are less serious. Treatments are aimed at prolonging the ability to move through physical therapy, surgery, and supportive devices such as crutches, braces, and walkers.

- Spinal cord injury causes loss of sensation and voluntary movement below the level of the injury. The degree of impairment depends on the area of the cord that is injured. For example, if the injury is on the upper part of the spine (the cervical area), the result is quadriplegia with paralysis in all four limbs, while an injury lower on the cord results in paraplegia which involves only the legs. Injury to the spinal cord can result from diseases such as cancer, infections, arthritis, or polio. These injuries more often result from accidents such as sports injuries, car accidents, falls, and gunshot wounds. Spinal cord injuries are not progressive but do require careful management to prevent urinary tract and respiratory infections, and extensive rehabilitation in independent living skills.

Fetal Alcohol Syndrome

Fetal Alcohol Syndrome (FAS) involves mild to severe mental and physical damage to the fetus caused by the mother's use of alcohol during pregnancy. FAS affects about 1 to 3 in every 1000 live births worldwide, and is the leading known cause of intellectual disability in the western world. French researchers at the University of Nantes in 1968 were the first to make a connection between maternal use of alcohol during pregnancy and birth defects in children. Five years later, American geneticists at the University of Washington in Seattle termed this condition Fetal Alcohol Syndrome.

Children with FAS are small at birth and have slow growth rates throughout their development. A child with FAS has characteristic facial features that may include short eye slits, a flattened mid-face, a smooth and elongated space between the nose and mouth, and a narrow upper lip. Children diagnosed with FAS show evidence of damage to the central nervous system that may be in the form of intellectual disability, learning disabilities, developmental disabilities, seizures, or small head size. A child with FAS may develop visual and hearing problems, heart defects, and other physical problems, and behavioral problems.

Researchers have found that some individuals who were exposed to alcohol during fetal development show only some of the characteristics of FAS. These individuals are described as having Fetal Alcohol Effects (FAE). However, both FAS and FAE individuals may have some degree of brain damage.

3. Normalization

Normalization means … "to the greatest degree possible and at any given time to offer a person life conditions at least as good as the average citizen." Some of these life conditions which we enjoy and which we must uphold and practice with people with developmental disabilities include:

1. being part of things – not being excluded
2. having the same opportunities and privileges as other citizens
3. interacting with non-disabled peers both in social and work situations
4. living in ordinary housing
5. receiving services without being segregated as a "disabled" group
6. not being labeled unnecessarily and never in a demeaning way
7. being treated with respect

Above and beyond any other rights mandated for the developmentally disabled, these life conditions are necessary for the individual with developmental disabilities to successfully integrate into society. Unfortunately, the attitudes of society are more often handicapping than the disability itself. If an individual is labeled or treated as being "different," that individual will most likely continue to think and act different. So it is important to stress what is "normal" and "appropriate" when training individuals with developmental disabilities.

To help individuals with developmental disabilities live normal lives, we can teach by building on what they can do. Remember the aim of normalization for individuals with developmental disabilities is to live as normal a life as possible. This would include living in a sexually integrated group, having privacy, experiencing normal daily living activities, such as eating with the family, choosing appropriate clothing and working outside the home. Everyone should have the freedoms of choosing how to spend their free time and seasonal activities. Opportunities must be available for individuals with developmental disabilities to detach themselves from their parents, Specialized Care Providers and other protective adults and try adult activities for themselves. One of the most important functions is to instill a sense of independence and to teach those skills and competencies which will enable people with disabilities to become as independent as possible. The individual placed in your home might not always make a choice that is acceptable to you, but the individual has a right to fail and learn from their mistakes and life experiences. You have a responsibility to protect their health and safety.

Bill of Rights

The Developmental Disabilities Bill of Rights (Section III of P.L. 94-103) guarantees persons with developmental disabilities their rights to these services by law, the same as the Bill of Rights assured basic rights to all citizens under the Constitution. These specific rights include:

- The right to treatment, services and habitation designed to maximize the developmental potential of the person and provided in a setting that is least restrictive of the person's personal liberty;
- The right to a nourishing, well-balanced daily diet;
- The right to appropriate and sufficient medical and dental services;
- The right to be free from physical restraint unless absolutely necessary, and in no event as a punishment or as a substitute for a habilitation program;
- The right to be free from excessive use of chemical restraints, and the use of chemical restraints as punishment or as a substitute for, or in an amount that interferes with services, treatment or habilitation;
- The right to receive close relatives as visitors at reasonable hours and without prior notice; and
- The right to be free from fire, safety, health and sanitation hazards in any facility providing services.

Choice and Self-Determination:

Each choice we make is an expression of our personal autonomy; our freedom to define who we are and what we value. The opportunity to make choices provides us with power to determine, to a great extent, what happens to us on a moment-by-moment basis, as well as over the span of our lives. To have the power to make choices taken away, for many of us, would be devastating if not unbearable!

D. Guess, H.A. Benson, E. Siegel-Causey
Concepts Related to Choice-Making And Autonomy Among Persons With Severe Disabilities. TASH 1985

Strategies for Honoring Choices

- Listen to the person
- Promote and explore options
- Clear role
- Build relationships and allies
- Make commitments
- Respect the person
- Be willing to bend rules and take risks

4. COMMUNICATION

Communicating with Family Members

Specialized Family Care providers will often need to communicate with the family members of individuals with developmental disabilities. You may need to provide progress updates, ask for information, or answer questions family members may have. It will be important to demonstrate respect for the family members and their concerns, and make sure that information is communicated clearly. Communication with family members is often a problem for people providing services. Sometimes, we fail to communicate well. This section will discuss the attitudes of family members and present strategies for communicating with family members.

The parent of a person with a developmental disability will typically experience many psychological changes in attitude about their child. These stages are:

1. grief
2. denial
3. guilt
4. embarrassment
5. rejection
6. hostility
7. depression
8. withdrawal
9. bargaining
10. acceptance

Communicating with People in the Community

To promote a positive image about individuals with developmental disabilities, people who work in the field need to develop positive communication skills when speaking to members of the community.

Images are very important, particularly for people who are already different from other people. In a society where intelligence is highly valued, individuals who have low intelligence may not be as valued as others. In a society that believes that getting around well in your environment, or communicating verbally are absolutely necessary, people who have trouble in these areas are often considered “a bother”. When people are considered different or deviant, special attention needs to be paid to the images surrounding them. Generally, there are two ways we can promote acceptance and integration for individuals with developmental disabilities:

1. By increasing the skills of people with developmental disabilities
2. By projecting a positive image of people with developmental disabilities

The language we use to describe people and the services they use can influence how others perceive them. Think of the difference between telling a new neighbor “we run a facility for profoundly retarded, multiply handicapped, non-verbal males” versus “We have created a home which supports people with disabilities in becoming contributing members of the community.” The first example presents a negative image. The neighbor is bound to walk away thinking, “Boy, those people must really be messed up.” The second creates a more positive image, and in fact describes what you are trying to do.

If we expect the community to treat residents with respect, we should model this respect:

- Calling a 45 year old man "Billy" and expecting him to call you "Mr. Jones" says something about the position you think he should be in.
- Discussing a person's history or present status with someone else while standing in front of the person shows little concern for his or her feelings.
- Constantly complaining to neighbors about "how hard it is to work with people like this" may help your image, but it makes other people feel that they should not attempt to become friendly with individuals with disabilities as it will be too demanding. If you really feel that your work is too hard, get some help.
- Using labels or descriptions that are dehumanizing or focus upon the disability instead of the individual.

Confidentiality is an important concern when talking about people with developmental disabilities to people in the community. Personal information such as medical diagnosis, behaviors, family information, financial and legal matters are never to be discussed. Questions about the people and programs you work with can be answered in ways which do not reveal private information.

In the community you may be required to answer questions, offer explanations, and respond to comments made by other members of the community. The following points will help you to communicate effectively:

- Answer factual questions simply and truthfully without breaking confidentiality Example: When asked, "What's wrong with the girl in the wheelchair?" Providers could respond that Jane does not walk and uses a wheelchair to move about in the community.
- When asked for an explanation, give a simple statement that is as complete as possible to avoid misinterpretations: Example: You are shopping at Kroger, as John pushes the cart down the aisles. He is reciting television commercials in a sing-song voice and finger flicking with his left hand. A shopper asks you why you are taking someone "like that" out in the community. Offer the following explanation: "John is learning how to grocery shop."
- Occasions may arise where members of the community offer comments to you about either the people you work with, behaviors they have observed, or the program in general. Thank them for their concern and tell them that you will relate their concerns to your supervisor or provide them with information for contacting your supervisor.