SPECIALIZED FAMILY CARE
Provider Training

Category:	**Advocacy**
Title:	**Lesson on History of Developmental Disabilities Services**
Materials:	Articles: "Parallels in Time: from **http://www.mnddc.org/parallels/one/1.html**: "Trans- Allegheny Lunatic Asylum Raises Awareness"; "Reasons for Admission"
Goal:	Specialized Family Care Provider knows the history of services to persons with developmental disabilities
Credit Hours:	1 Hour
Date Developed:	May, 2011, Updated March 2017
Developed by:	Donna McCune, SFC Program, Updated by Carol Brewster, March 2017

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

3/16/2017

Specialized Family Program Manager **Date**

Carol Brewster 03-14-2017

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

Training Objectives:

- Specialized Family Care Provider knows how services to individuals with disabilities has changed over the years
- Specialized Family Care Provider knows the continued needs of individuals with developmental disabilities
- Specialized Family Care Provider is aware of West Virginia's role in provision of services to individuals with developmental disabilities

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**

This Program is funded by the WV Department of Health & Human Resources, Bureau for Children & Families and administered by the Center for Excellence in Disabilities, West Virginia University

Trans-Allegheny Lunatic Asylum Raises Awareness

A national historic landmark in Weston, West Virginia, serves as a stark reminder of the history of care for individuals such as those served by the Center for Excellence in Disabilities, Specialized Family Care Program. A visit to the Trans-Allegheny Lunatic Asylum (formerly known as Weston State Hospital) can be overwhelming to those who visit, with emotions ranging from shock and sadness to jokes and teasing to lighten the mood. Some visit to gain a historical perspective on where we have been and how far we have come in provision of services to individuals with a developmental disability. Still others come seeking entertainment, participating in ghost hunts throughout the structure. Hopefully, all come away with knowledge of how the Trans-Allegheny Lunatic Asylum came to be and why it no longer exists.

An understanding of how and when this West Virginia structure came to be, along with other similar facilities in West Virginia (Colin Anderson Center, Greenbrier Center, Huntington State Hospital, Spencer State Hospital) begins by looking back in history. The history of developmental disabilities dates back to ancient times when people struggled to explain their world. Physical difference was viewed as a mark of inferiority. The first recorded reference to "mental retardation" was found in an obscure document. There were no historians recording the lives of persons with disabilities.

During the Middle Ages after the fall of the Roman Empire all people were struggling, but for people with disabilities it was also marked by indifference, neglect, and fear. Those who received recognition often served as "fools" and court jesters employed to entertain nobility. The Roman Catholic Church created the first asylum to provide refuge to those in need, establishing orphanages and hospitals and homes for the blind and aged. The first asylum for abandoned infants was created. Intended to meet a need, conditions were custodial and overcrowded and most children did not survive. "Idiot cages" became common in town centers "to keep people with disabilities out of trouble."

A historical reference to the 17th and 18th centuries states that this period witnessed a more constructive, scientific approach to persons with disabilities. However, this approach did not better the plight of individuals with disabilities.

Persons with disabilities continued to experience harsh conditions in the early 19th century. Often they were placed into what was known as poorhouses, along with others who were experiencing poverty, sometimes due to being widowed or alcoholic. Some were even jailed where neglect and torture were not uncommon. There were no state hospitals or mental health services available. A young woman named Dorothea Dix surfaced and began to tirelessly work to improve the conditions for this vulnerable population.

Dorothea Dix's efforts, along with a physician, Dr. Thomas Kirkbride, resulted in the first "lunatic" asylum to be built in New Jersey. Other states followed suit, and in 1864 the Trans-Allegheny Asylum, subsequently Weston State Hospital, opened in Weston, West Virginia modeled after the "The Kirkbride Plan" of architecture, which was to build a structure conducive to curing, with sunlight and fresh air being available to all. Weston State Hospital was a Kirkbride psychiatric hospital that operated from 1864 until 1994. It is the largest hand-cut stone masonry building in North America, and is purportedly the second largest in the world, next to the Kremlin. Intent was to provide a sanctuary for 250 persons.

This West Virginia "sanctuary" quickly became overcrowded and at one point housed 2600 persons. Individuals could be brought to the facility for insignificant reasons. (See the attached listing of examples of reasons for placement.) They remained until a doctor said they were cured or until someone came to get them out.

It was the work of the Portuguese neurologist António Egas Moniz in the 1930s that led to a wider use of psychosurgery. Moniz, working with neurosurgeon Pedro Almeida Lima, started operating on patients in late 1935. The first operations involved injections of alcohol into the frontal lobes of patients to destroy white matter; Moniz then devised an instrument he called a leucotome to remove small cores of white matter. He coined the terms *leucotomy* and *psychosurgery*. Moniz's methods were taken up in the United States by the neurological team headed by Walter Freeman II and the neurosurgeon James Watts. A form of treatment, which we now consider to be barbaric, was performed. Dr. Walter Freedman II, a nationally known physician, frequented the facility and performed lobotomies, a procedure whereby a pick like instrument was inserted into the eye cavity, reaching the brain, where is maneuvered similar to a windshield wiper. The intent was to cure the person of their mental illness or other disabilities. Dr. Freedman II was praised for his ability to perform 50-100

lobotomies per day, completing each procedure in 10 minutes. Staffing at the facility was limited, resulting in poor living conditions for the individuals living there and poor working conditions. Walter Freeman II nominated his mentor <u>António Egas Moniz</u> for a <u>Nobel Prize</u> and in 1949 Moniz won the Nobel Prize in physiology and medicine for the staff. By the time Weston State Hospital closed, there was an average of over one death per day.

Despite the horror stories which were a result of this period in history, there are courageous stories of the efforts of determined individuals to help better the lives of persons with disabilities. There was staff who dedicated their career and lives to working within the institutions because they cared. Those who brought their loved one there to live did not always do so because they did not care, but because it was the recommended treatment at that time, and they visited often.

Outside the institution, during the late 1940's and early 1950's advocates, many of whom were parents of persons with disabilities, began to organize and demand better service. During the 1960's and 1970's these groups worked on improving conditions in state institutions, creating community services. People became more comfortable speaking out about their family members with disabilities. Lawsuits began to be filed to force states to recognize civil and legal rights. One such suit, The Medley Class Action, was filed in West Virginia on April 21, 1987. (Medley vs. Ginsberg) When the Medley Consent Decree was signed, conditions began changing in all of West Virginia's institutions, closing several, with the remainder to later follow. The Decree mandated that all services to persons with disabilities be delivered in a "least restrictive environment". When the lawsuit began there were 232 children under the age of 18 living in state institutions. Today, there are none. Instead, most individuals are at home with their families, in a small group homes or with families through the Specialized Family Care Program. Today, an on-going self-advocacy movement made up of persons with disabilities as well as those who do not have intellectual disabilities, continues to work to improve services throughout communities for those who have disabilities.

Weston State Hospital was auctioned by the state in 2007, and purchased by a Morgantown businessman. Amid protest by mental health advocates, the name Trans-Allegheny Lunatic Asylum was chosen for the building, and it was opened for tours to the public in 2008. Today, tours are conducted throughout the property and building which covers 9 acres of floor space. Amid the crumbling walls and leaky ceilings, tourists can view the rooms in which individuals lived,

including seclusion rooms intended to calm violent patients. On display are Electra-shock therapy boxes and lobotomy instruments. Down in the basement are the operating rooms where lobotomies were performed, as well as a "holding" room for those who had passed away. Life was sustained in this facility which was essentially a small "city" and some patients rarely, if ever, left the premises.

Thanks to programs such as Specialized Family Care, services to a vulnerable population are being met in a much more humane way. The WV Specialized Family Care Program is essentially a WVDHHR foster care program funded and administered by the Bureau of Children & Families, Division of Children and Adults.

The Specialized Family Care (SFC) program supports individuals, both children and adults, with intellectual/developmental disabilities in homes, neighborhoods and communities.

Advocacy groups and other caring agencies and services are available to monitor and protect individuals in care. Continued work is needed but, hopefully, historians will look back upon our era positively, using it as a model for continued improvement for service to those with disabilities.

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Parallels in Time

From: http://www.mnddc.org/parallels/one/1.html

The Ancient Era
1500 B.C. – 475 A.D.

Ancient people struggled to explain their world. Natural phenomena, such as storms or the change of seasons, were attributed to gods or some sort of intervention by higher beings. Thor controlled the sky, Neptune the sea.

People became more rational, however, when they tried to explain one another. The great philosopher Socrates (470 - 399 B.C.) was concerned primarily with ethical questions, such as what makes a good life.

The year 1552 B.C. marks the first recorded reference to mental retardation, scribed in an obscure document called the Therapeutic Papyrus of Thebes. Unlike today, the Ancient Era had no historians recording the lives of persons with disabilities.

The Greeks and Romans in particular held a very narrow sense of self-image, believing they exemplified the ideal human type. With their contributions to art, philosophy, literature, and science, they viewed themselves as superior to all other races. Physical difference, in the form of a different ethnicity or a disability, was seen as a mark of inferiority.

There are few references to disabilities, and nowhere in writing did the Ancients ever ponder what could be done to make living with a disability more bearable or acceptable. The Greeks referred to people with intellectual deficiencies as idiots.

In Rome, children with disabilities were treated as objects of scorn. Children who were blind, deaf, or mentally retarded were publicly persecuted and reported to have been thrown in the Tiber River by their parents. Some children born with disabilities were mutilated to increase their value as beggars. Other children born with disabilities were left in the woods to die, their feet bound together to discourage anyone passing by from adopting them. In the military city of Sparta, the abandonment of "deformed and sickly" infants was a legal requirement.

With the rise of Christianity, there was a gradual influence on how persons with disabilities were treated. Jesus Christ (6 B.C. - 30 A.D.), called "The Great Physician," showed compassion for persons with disabilities. In the New Testament, Jesus is frequently credited with showing kindness and performing miraculous cures of those who were "lame, blind, and otherwise disabled". St. Paul directed Christians to "comfort the feeble-minded."

By the fourth century A.D., the rise of Christianity led to more humane practices toward persons with disabilities. Infanticide (the practice of killing children) ceased and helping "the afflicted" became a sign of strength.

The Middle Ages, Renaissance, and Reformation

476 A.D. – 1500 A.D.

After the fall of the Roman Empire in the 5th century, Western Europe simply fell apart. The tight control of the Roman government was destroyed by the invading barbarians, turning a once unified continent into a collection of hundreds of small communities.

The value placed on education, science, and art during the Roman Empire was gone. Life was hard for almost all Europeans. For people with disabilities, the period was marked by indifference, neglect, and fear. As in Roman times, people with physical disabilities, mental illness or intellectual deficiency were the "fools" and court jesters employed to entertain nobility.

The Middle Ages was a time dominated by the idea of God. The notion that people with disabilities were "Children of a Caring God" (Les enfants du Bon Dieu) was prevalent. People with disabilities were considered "different"; none were considered normal.

During this time, "idiot cages" became common in town centers to "keep people with disabilities out of trouble." They may have served as entertainment for townspeople

During the Middle Ages, the Roman Catholic Church provided refuge to those in need, establishing orphanages, hospitals, and homes for the blind and the aged. In 787 A. D., Datheus, archbishop of Milan, founded the first asylum for abandoned infants. "As soon as the child is exposed at the door of the church," he wrote, "it will be received in the hospital and confined to the care of those who will be paid to look after them." Conditions at such institutions were custodial at best, and most children did not survive.

The 17th and 18th Centuries

The history of disabilities prior to the 17th and 18th centuries has been referred to as "a [time] of confusion," lacking in understanding of, and services for, persons with disabilities. However, the 17th and 18th centuries witnessed a more constructive, scientific approach to individuals with disabilities. The earlier efforts of Sir Isaac Newton and Galileo contributed to an understanding of the physical world, while philosophers of the time tried to understand human nature.

With the industrial revolution of the 18th century, more and more people flooded into cities, working for slave wages and living in squalid conditions. Children represented a large portion of the work force, performing grueling work for twelve to sixteen hours per day. Pauper children were often contracted to factory owners for cheap labor. To get rid of "imbecile" children, parish authorities often bargained with factory owners to take one "imbecile" with every twenty children.

The Rise of the Institutions
1800-1950

Living conditions for persons with disabilities in the early 19th century were harsh, especially in industrial areas. Persons who lived in poverty, whether it was due to being widowed, orphaned, alcoholic, or because of physical or mental disabilities, often were put into poorhouses, or almshouses. Wealthier parents tended to keep their children with disabilities at home.

A common practice in the early 19th century was "warning out" individuals with disabilities and others considered deviant. Warning out was informing an unwanted newcomer that he or she was not welcome in their town. "Passing on" was another popular practice. This entailed loading persons onto a cart and dropping them off in the next town.

Around the 1820s, amid a climate of enormous wealth in the growing industrial cities, a large number of rural and urban people were suffering from extreme poverty. During this age of rapid mechanical progress, industrialization, and scientific and medical achievement, people began to speak out on the conditions of persons with disabilities and others who were oppressed or neglected.

An increased interest in persons with disabilities in the early part of the 19th century found its way to social practice by 1850. At this time, social reformers such as Dorothea Dix were advocating for better services for all persons with disabilities, many of whom were living in appalling conditions.

Since it was unthinkable in 1848 for a woman to address Congress, Dix had Samuel Gridley Howe, a well-known social reformer, present her speech. Her specific appeal – that the United States set aside 5 million acres of land throughout the nation to accommodate persons with disabilities – was passed by both houses of Congress but vetoed by President Pierce. Through her passionate appeals, and with only the best intentions for persons with disabilities, Dix helped to prepare the way for public institutions.

With proper training, it was believed, many persons with disabilities could be educated to return to the community and lead productive lives. Optimism for the early "training schools," the increasing awareness of the numbers of persons with disabilities, and reformers such as Dorothea Dix, resulted in an increase in the number of institutions. At this time, the underlying belief was that through proper education and humanitarian means, we could "make the deviant undeviant" – we could change them to fit better into the world.

Teaching methods led to improvements in physical development, behavior, and social skills. The experimental training schools were a success. Intellectual deficiency was, of course, not "cured," but many pupils with mild and moderate disabilities profited from their training; they developed the necessary skills to return to their families and communities.

Unfortunately, during the economic troubles of 1857 and as a result of the Civil War, there simply were no employment opportunities for returning pupils. Competition for jobs was already high, with immigrants willing to work for low wages. Historian James W. Trent noted, "In a growing and increasingly industrialized nation, communities did not need idiots, not even educated ones." Pupils who returned to their communities looking for work usually ended up in poorhouses or jails.

At the same time, there was an increasing demand for placement in training schools. Many parents had heard success stories and some believed that intellectual deficiency could even be cured. Existing training schools expanded their facilities and began serving persons with all types of disabilities.

While the number of training schools increased, the commitment to training did not. The schools quickly became asylums, providing custodial care for an increasing number of individuals with developmental disabilities. As enrollment increased, the commitment to education was largely abandoned. Pupils became "inmates ." Through the 1870s and 1880s, a few institutions continued a policy of admitting persons of a young age who were considered capable of benefiting the most from instruction. But by 1875, a number of states began building **custodial institutions.**

One method of institutional expansion was the development of farm colonies. Purchasing cheap farm land and abandoned farms in depressed rural areas, superintendents built housing for a small number of "high-grade" residents and a few staff persons.

This period was marked by the emergence of special education. As teachers in public schools became aware of the increasing numbers of students with learning disabilities who were labeled "backward" or "feebleminded," they called for special classes and teachers to educate them. Rhode Island opened the first public special education class in the U.S. in 1896. By 1923, almost 34,000 students were in special education classes.

The Reawakening
1950 – 1980

During the late 1940s and early 1950s, there was a reawakening of hope and possibilities for persons with disabilities. Frustrated and angry over poor living conditions and the lack of community services, parents began to organize and demand services for their sons and daughters. The efforts of a few groups of parents, scattered across the United States, led to a strong, national movement of parents who declared "The Retarded Can Be Helped."

During the 1960s and 1970s, the parents' movement worked on improving conditions in state institutions; creating community services, educational and employment opportunities; initiating legislation; and challenging the conventional wisdom that person's with disabilities could not be helped. After years of treating people with mental retardation and other disabilities with guilt and shame, people began to speak about their family members with disabilities.

President John F. Kennedy, whose sister Rosemary had mental retardation, launched the President's Panel on Mental Retardation and developed a "plan to combat mental retardation." Parent organizations filed lawsuits to force states to recognize the civil and legal rights of their children. Laws were passed to enforce these rights, services were established and delivery systems were required to provide appropriate services to children and adults with disabilities. Actions were begun to close public institutions and assure that people with disabilities could live in and be a part of the natural community.

The American Association on Mental Deficiency adopted mid-century objectives, including adequate and suitable facilities, care and training, community placement, and special classes for children and adults with mental deficiencies. The National Association of Parents and Friends of the Mentally Retarded, later to become "The Arc", was founded "to promote the welfare of the mentally retarded of all ages everywhere: at home, in the community, in institutions, and in public, private, and religious schools."

Doctors continued to urge parents to place their children in institutions regardless of the conditions. Between 1946 and 1967, the number of persons with disabilities in public institutions increased from 116,828 to 193,188, a rate increase nearly twice that of the general population. Institutions began admitting younger children with more severe disabilities.

During the post-war boom in America, having a "**handicapped**" child was seen as a burden to the family. More and more children were institutionalized and not just children from poor families. This practice is what Albert Deutsch referred to as "euthanasia through neglect."

The 1960s was a time of great change and societal upheaval in the United States. The Civil Rights movement was underway. Dr. Martin Luther King, Jr. proclaimed that "children will one day live in a nation where they will not be judged by the color of their skin but by the content of their character." President Lyndon B. Johnson aspired for a Great Society and began the War on Poverty.

In 1962, a report of the President's Panel on Mental Retardation concluded that the quality of services in state institutions should be upgraded. Local communities were encouraged to work with federal and state agencies to provide a comprehensive, community-centered continuum of services. In 1963, federal funds were authorized for the construction of community facilities for people with mental retardation.

In 1974, President Richard Nixon issued Executive Order 11776 reaffirming the national goal of returning about one-third of the 200,000 people with mental retardation in public institutions to community residential placements. The Justice Department was directed to strengthen the full legal rights for people with mental retardation. Amendments to the Social Security Act authorized residential care in Intermediate Care Facilities and established the Supplemental Security Income program.

Amendments to the Rehabilitation Act required that people with severe disabilities be given priority for vocational rehabilitation services; Section 504 prohibited discrimination against people with disabilities in federally funded programs.

The Developmental Disabilities Assistance and Bill of Rights Act required states to plan for community alternatives to institutionalization.

The United States District Court for the District of Minnesota, in Welsh v. Likins, held that people with mental retardation have a constitutional right to treatment in the least restrictive environment.

The grassroots efforts of the early parents' movement, most notably the Association for Retarded Children, were successful in achieving far-reaching change for persons with disabilities and their families. These parents, acting out of a sense of urgency, challenged public attitudes about their children and educated their legislators about the unfair treatment that their children received in housing, education, and employment.

For many younger parents of children with disabilities, the choice has not been to join existing organizations, but rather to become educated and advocate on behalf of their children. With many basic services in place, the role of the parent has shifted from fighting for basic rights to ensuring that their local communities honor existing rights and provide the individual services required.

Older parents are being encouraged to recognize that as their sons and daughters become adults, they are entitled to make their own decisions and live as independently as possible.

The Independent Living Movement

1970

The concept of independent living is opposite that of the institutions, and a movement away from dependency on parents and professionals. Essentially, independent living means the opportunity to make decisions that affect one's life, being able to pursue activities of one's own choosing. Independent living does not necessarily mean living alone. Rather, it has to do with self-determination: making choices, being allowed to fail, and having access to appropriate services.

Pioneers like Ed Roberts refused to accept a segregated life and demanded more control of his own life. This was the start of the Independent Living Movement. For the first time, persons with disabilities were the decision makers.

Centers for Independent Living offer a range of services for persons with disabilities. Under the Rehabilitation Act Amendments of 1993, Centers are mandated to provide four "independent living core services" and may provide any of the other independent living services that are specified in the Amendments.

The Self Advocacy Movement
1980

Self-advocacy, quite simply, means advocating for one's self, standing up for one's rights. For thousands of people with disabilities around the world, self-advocacy is a term of personal identity, focusing on one's political power and right to self-determination. It is also a civil rights movement that represents individuals of all races, colors, and religions who have been systematically neglected, abused, incarcerated, and misunderstood for most of history.

In 1995, over 600 self-advocacy organizations existed in the United States, including the national organization Self-Advocates Becoming Empowered. Self-advocacy groups have also sprung up in a dozen other nations.

Under pressure from self-advocates, the Association for Retarded Citizens (ARC) became The Arc, and the American Association on Mental Deficiency (AAMD) changed its name to the Association on Mental Retardation (AAMR). Self-advocates are saying loudly that they are no longer the objects of professionals or the "mentally retarded" patient; nor are they the "eternal children" of the early parents' movement. "We are People First," and the disability should be considered second, if at all.

REASONS FOR ADMISSION
WEST VIRGINIA HOSPITAL FOR THE INSANE (WESTON)
OCTOBER 22, 1864 to DECEMBER 12, 1889

Amenorrhea
Asthma
Bad company
Bad habits & political excitement
Bad whiskey
Bite of a rattle snake
Bloody flux
Brain fever
Business nerves
Carbonic acid gas
Carbuncle
Cerebral softening
Cold
Congestion of brain
Constitutional
Crime
Death of sons in the war
Decoyed into the army
Deranged masturbation
Desertion by husband
Diphtheria
Disappointed affection
Disappointed love
Disappointment
Dissipation of nerves
Dissolute habits
Dog bite
Domestic affliction
Domestic trouble
Doubt about mother’s ancestors
Dropsy
Effusion on the brain
Egotism
Epileptic fits
Excessive sexual abuse
Excitement as officer
Explosion of shell nearby
Exposure & hereditary
Exposure & quackery

Exposure in army
Fall from horse
False confinement
Feebleness of intellect
Fell from horse
Female disease
Fever
Fever & loss of law suit
Fever & nerved
Fighting fire
Fits & desertion of husband
Gastritis
Gathering in the head
Greediness
Grief
Gunshot wound
Hard study
Hereditary predisposition
Ill treatment by husband
Imaginary female trouble
Immoral life
Imprisonment
Indigestion
Intemperance
Interference
Jealousy
Jealousy & religion
Kick of horse
Kicked in the head by a horse
Laziness
Liver and social disease
Loss of arm
Marriage of son
Masturbation & syphilis
Masturbation for 30 years
Medicine to prevent conception
Menstrual deranged
Mental excitement
Milk fever
Moral sanity
Novel reading
Nymphomania
Opium habit
Over action on the mind
Over heat

Over study of religion
Over taxing mental powers.
Parents were cousins
Pecuniary losses: worms
Periodical fits
Political excitement
Politics
Puerperal
Religious enthusiasm
Religious excitement
Remorse
Rumor of husband's murder or desertion
Salvation army
Scarlatina
Seduction
Seduction & disappointment
Self-abuse
Severe labor
Sexual abuse and stimulants
Sexual derangement
Shooting of daughter
Smallpox
Snuff
Snuff eating for two years
Softening of the brain
Spinal irritation
Sun stroke
Sunstroke
Superstition
Suppressed masturbation
Suppression of menses
Tobacco & masturbation: hysteria
The war
Time of life
Trouble
Uterine derangement
Venereal excesses
Vicious vices in early life
Women
Women trouble
Young lady & fear

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