**Introduction to Developmental Disabilities**

**Online Content: Modules 1,2,4,5**

These lessons offer the participant a background in the history, language, and basic concepts of services for persons with developmental disabilities. The information is meant to identify what the terms “developmental disability” and “intellectual disability” mean as well as begin to sensitize the participants to prejudices, stereotypes and myths of society around the issues of disability.

The following are the objectives for the On-line lessons in CDS. You may want to review them with learners at the start of the class.

**Lesson 1: A Brief History of Developmental Disabilities**

1. Describe social attitudes and the treatment of people with [developmental disabilities](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Developmental Disability(ies)) at critical times in Western history.
2. Describe three models of viewing people with developmental disabilities that help us understand historical and current views.
3. Describe some of the beneficial and harmful effects that the [moral](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Moral Model), [medical](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Medical Model), and [minority model](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Minority Model)s have had on attitudes and treatment of people in history, and their influence today.
4. Describe some ways in which historical and current views of disability are similar and different across cultures.
5. Describe current and anticipated challenges for people with developmental disabilities in regards to general acceptance of the Minority Model of disability.
6. Describe the historical role of direct support professionals and their important role in supporting and fostering positive lifestyles for people with developmental disabilities today.

**Lesson 2: The Language and Ideas of Best Practice**

1. Describe the importance of language choice in our daily and professional lives.
2. Define the term “[best practices](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Best-Practices).”
3. Describe and define some important terms related to current best practices including: [circle of support](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Circle of Support); [consumer-directed](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Consumer-Directed); [deinstitutionalization](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Deinstitutionalization); [dignity of risk](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Dignity of Risk); [direct support professional](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Direct Support Professional  (DSP)); [inclusion](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Community Inclusion:); [integration](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Integrated Integration:); [natural supports](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Natural Supports); [normalization](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Normalization); [person-centered](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Person-Centered); [people first language](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#People-first language); [self-advocate](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Self-Advocate); [self-determination](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Self-Determination); [support coordination](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Support coordination); and [support teams](http://www.collegeofdirectsupport.com/Content/Sertoma/tn736mastgloss.htm#Support Team).

**Lesson 4: Causes of Developmental Disability**

1. Describe the two most common things that can cause developmental disabilities.
2. Describe some of the major genetic and environmental factors that can cause developmental disabilities.
3. Describe why knowing the causes of a developmental disability may affect the support you provide.
4. Identify and use strategies to get additional information about specific conditions.

**Lesson 5: Services for People with Developmental Disabilities**

1. Describe the difference between services and support.
2. Describe the difference between specialized and generic services.
3. Describe methods of payment for specialized services.
4. Describe service coordination and how services are organized.
5. Describe common specialized services that people with developmental disabilities use including: family support services; residential services; special education services; and vocational services.
6. Describe changes in the service system and how those are affecting people with developmental disabilities and direct support professionals.

Class Session: Introduction to Developmental Disabilities

(1 hr.)

**Outcomes of Live Session**

1. Define the term “developmental disability” and differentiate from “mental illness”
2. List the components of Maine’s definition of intellectual disability
3. Identify common developmental disabilities
4. List common myths about people with an intellectual disability
5. Identify current trends and best practices for people with developmental disabilities
6. Develop a list of ‘age appropriate’ activities

**Sample Questions / Topics for Discussion**

* Discuss the definition of ‘developmental disability’ and ask:

1. Is Mental Illness a Developmental Disability?
2. How is Mental Illness different from a DD?”

* Discuss Maine’s definition of Developmental Disability and list the qualifying components for Maine services
* Discuss the common disabilities and ask the following:

1. “What stereotypes or myths exist for people with DD; Autism; Seizure Disorder; Cerebral Palsy?” “What are the facts?”
2. How do DSPs play a role in diminishing the stereotypes?

* Discuss current trends and best practices. Go over the Disability Etiquette pre-quiz.
* Discuss the difference between physical age and cognitive age and how it ties in with age appropriateness. Also discuss age appropriate activities. Ask the following:

1. How would you best support an individual who is physically 35 years of age with a cognitive age of 9?
2. Is it age appropriate for adults to go trick or treating? Go to a school playground and play with the children on the swings? What are some alternative age appropriate activities?
3. How is doing age inappropriate activities perceived by the community? (carrying dolls around at the grocery store, playing with children at the playground; attending story time at the children’s library)

**Handouts**

* *A Brief History of Pineland Center(below)*
* *Current System of Maine Services (below)*
* *Government Involvement and Management of Services (below)*
* *A Brief Timeline of Maine Intellectual Disability Services*
* *Disability Etiquette: Tips On Interacting With People With Disabilities (see link below)*

**Resources / Links**

**Disability Etiquette** <http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf>

**A Brief History of Pineland**

Before what became known as the Pineland Center was founded in 1908, people with developmental disabilities lived in a variety of situations. Children generally remained at home, with the more capable attending the small, un-graded one-room schools of the day, while more handicapped individuals went without schooling. Adults who were able were useful in the simpler farmstead technology of that time, while less able adults were cared for at home within the extended family, or maintained on poor farms or on other forms of town welfare.

The small town or village of yesteryear often provided a closely-knit, supportive group for nearly all its members. Some were sent from Maine to the Massachusetts School for the Feebleminded (later named the Walter E. Fernald State School), on which the Maine school was apparently modeled.

In 1908 the Maine School for the Feebleminded (a term not then considered offensive), was opened. In later years it was renamed the Pownal State School, then Pineland Hospital and Training Center, and finally Pineland Center. The facility in Maine was founded in response to a number of rather diverse, even contradictory, needs that were seen as valid at that time. These included the need for special education and care for those with developmental disabilities, the towns’ need to reduce their welfare costs, and the need to protect people with disabilities from exploitation or neglect in the community.

There was also another need perceived at that time – that of protecting the community from people with intellectual disabilities. Several genealogical and social studies, along with their proponents, had wrongly identified people with intellectual disabilities as being the cause of almost all crime, social ills, and poverty of that period.

The institution was located in New Gloucester because it was a rural setting, but it was reasonably close to several major cities and Maine’s population center. There was also ready access to major railroad lines and two railroad stations less than a mile from the school. This made it easier for people and freight to be brought to and from the institution.

The original plan for the school, which was on 1500 acres and said to have had a good supply of water, was that it would be a farm colony, largely self-sufficient and self-supporting. It was believed that this environment would bring the residents the benefit of “lots of fresh air and sunshine.” Both the residents and the employees were required to live on the grounds. The more capable male residents, called the “working boys”, provided labor for the farm operations, which included dairy cattle and draft horses, growing vegetables, and raising pigs and chickens. The more capable female residents, called the “working girls”, had domestic duties, including making clothing and mattresses, preparing food, cleaning the buildings, and the care of the less capable residents. All of the residents were called “children” regardless of their ages, and men and women were kept strictly separate.

Training at the school was provided for younger children through 6th or 8th grade, but practical work training – farm, industrial and domestic – was the education for older, more capable male and female residents. The “working boys and girls” were also hired out to local farms on “trial visits” that often lasted many years. They were an inexpensive source of male labor for farms and female labor for private homes or nursing homes. As late as the 1950s, the pay they received was room and board at the home they were hired out to, plus three or even five dollars every other week.

While employees could resign and leave, the residents stayed involuntarily. Discharge was possible, but rare. For most residents, commitment to the school was a life sentence. The school put on its best face with sports, entertainments, and festive holidays, but residents who tried to escape were usually soon captured and faced severe, even cruel discipline.

The school grew rapidly after its founding in 1908. New buildings, dormitories and barns were added. Two years later, in 1910, there were 135 residents, and within six years, by 1914, there were 300. The 1914 annual report showed prosperity, growth and efficiency – made possible by the unpaid labor of the “working boys and girls” who were supervised by employees. Again, it’s important to remember that the children who were sent to the institution were not free to leave.

During the 1920s and 1930s the school pursued what was a previously limited goal of saving the state of Maine from the “mentally deficient”. In this way the institution grew from its primary role of training and agriculture to a more judgmental role of “protecting society.” Official statements about the dangers to society from “the menace of the moron” grew shriller, more alarming and, apparently, more convincing. The state legislature committed more funds to the expansion of the school and its mission to impound all people with intellectual disabilities and prevent them from having children.

Warehousing was in order. Buildings were designed to house 80, then 150 children in large open wards. The ultimate was achieved in 1950 with the opening of Bliss and Kupelian Halls, which allowed the admission of 479 more residents. By the mid-1950s the total resident population on the grounds was nearly 1500, and the total of those ‘on the books’ was well above that number. Employees numbered only 240. There was unbelievable crowding, and conditions in the buildings for the severely and profoundly ambulatory developmentally disabled were truly unspeakable.

It is important to realize that many of the children who were sent to what is now Pineland did not have intellectual disabilities. They could have functioned well in the community but were sent to the school at an early age. They came mostly from poor families, often from broken homes, and scored poorly on the early intelligence tests, which were academically oriented. In many cases these children were labeled as “morally” or “economically” feeble-minded.

What is remarkable is to realize that in spite of the increasing numbers of children who were being sent to Pineland, the vast majority of the children and adults with intellectual disabilities in Maine (estimated at up to 25,000) continued to live in their communities, and never went to Pineland.

In spite of the expansion that took place in the 1950s, the myth of the danger to society from people with intellectual disabilities was being disproved in many research settings. New philosophies and new social and political forces were at work and made the research heard. By the mid-1950s there was an abrupt change of policy at Pineland; the emphasis was on placing the “working boys and girls” in community employment, followed by discharge from Pineland. Despite initial objections from some sheriff’s departments which had been told many times about the “menace” of “these people,” the discharge policy was pursued, and several hundred former Pineland residents who either worked to maintain Pineland, or had been hired out to other farms and families, eventually became self-supporting and independent in their communities.

The 1960s and 1970s were marked by several advancing trends at Pineland. There was a continuing reduction of the number of residents living on the grounds. There was also a change in the nature of the resident population as federal and state social programs enabled more people with moderate and even severe disabilities to be discharged into more suitable sheltered community living.

Pineland began to develop its specialized services and therapies – special education, psychology, medicine and biogenetics, occupational and physical therapies, social work, audiology and communication. As the more capable residents departed, the individuals providing these therapies and services were able to focus their skills on the remaining residents, helping them to maximize their potential and, in turn, make many of them eligible for community placement. There was also a gradual improvement in resident living conditions, from the barracks-style open wards with wall-to-wall beds to smaller, separate quarters.

By the early 1970s there was turmoil at Pineland. Some people saw a need for the total elimination of the facility, since they saw any institution as evil. Others sought continuation of Pineland with internal improvements and a more defined purpose. The facility itself was the battleground for these conflicting forces; while there had been five Superintendents in the 63 years from 1908 to 1971, there were ten personnel changes from 1971 to 1979. Newspaper stories exposed the poor conditions to public view. Also in the 1970s there were class action lawsuits on behalf of minorities seen as mistreated or neglected, including people with physical or intellectual disabilities.

In 1975 a class action law suit was filed in Federal District Court in Portland to improve conditions and treatment at the facility. In 1978 a detailed agreement called the Pineland Consent Decree was reached between the Department of Mental Health and Mental Retardation and the attorneys for residents of Pineland. The class of residents covered by the agreement included all individuals who were under involuntary commitment to Pineland on or after July 3, 1975, whether they were actually at Pineland or in community placements at the time. Time frames were set for the achievement of rigorous standards for treatment, both for those at Pineland and for class members in the community.

The response to the Consent Decree was to make tremendous efforts to create and improve services both at Pineland and in the community. Individual program plans were developed for each class member, along with methods to implement the plans and address identified needs. Residential units at Pineland became smaller and more homelike, with ‘apartments’ of four to six people, and only one or two people to a bedroom.

In 1981 the Federal District Court declared that Pineland was in substantial compliance with the standards of the consent decree making Pineland the first state residential facility in the nation to be released from court jurisdiction.

By early 1982 the Pineland population was reduced to 330, the majority being people with multiple disabilities – cognitive, physical, sensory, medical and behavioral. Admissions were limited to short-term respite, emergency, or special cases requiring medical, dental or behavioral intervention. Increased emphasis was placed on Pineland’s role as a professional education resource.

The community service system continued to grow and develop its capacity to serve individuals with more complex needs. In 1983 Special Master Lincoln Clark reported to the Federal Court, “I am especially proud that Maine is the first state to be found in compliance with a comprehensive Federal Court decree aimed at improving the welfare of the mentally retarded. Compliance does not mean that all class members currently receive every amenity and service stipulated in the decree. It means that ‘all systems are go’ and that nothing in the state’s system of care and services impedes the full realization of decree rights to each individual.”1

While court jurisdiction of the Pineland Consent Decree ended, the standards were incorporated into the systems and services at Pineland and in the community. Throughout the period of the 1980s into the 1990s and beyond, additional federal funding was made available through the Intermediate Care Facilities for Individuals with Developmental Disabilities (ICF/IID) and Medicaid Waiver programs, now termed the MaineCare Home and Community Based Waiver

However, in the early 1990s the Consumer Advisory Board, which had been created to monitor compliance with the Pineland Consent Decree, determined that Maine’s intellectual disability service system fell short in the delivery of some services. In September 1994 a new agreement, known as the Community Consent Decree, was signed in Federal District Court. This consent decree continued to cover Pineland class members and established standards and expectations in the areas of: Personal Planning, Crisis Prevention and Intervention, Professional Services, Resource Development, Appeals Process, Consumer Advisory Board, Budget, as well as policies, organization, training and other requirements.2

While the Community Consent Decree took no position regarding the closure of Pineland, realities of the declining resident population focused attention on the class members living in community settings. The resident population dwindled from 207 in late 1992 to 140 in early 1994 and 76 a year later. As the population decreased the cost of maintaining staffing, as well as upkeep for the grounds and aging buildings rose. In spite of the concerns expressed by some families and employees who were concerned that adequate services would not be available outside of Pineland, community placements continued. The last resident left Pineland, and the facility closed in June 1996. With the closure of Pineland Maine joined New Hampshire and Vermont as the only states in the nation at that time to have eliminated their large state institutions for people with intellectual disabilities.

Pineland was similar to many other state schools across the nation in its origins, its successes and its shortcomings. Through all the changes in its history it reflected the best and worst of prevailing social attitudes towards people with intellectual disability and the state’s role in providing for them.

Adapted from “A Brief History of Pineland Center” by John Hoffman

For additional information, see Pineland’s Past: the first one hundred years by Richard S. Kimball, Peter E. Randall Publisher, 2001

1 Report to the Court on the Martti Wuori Case – Lincoln Clark October 1983

2In April 2010 the Federal District Court found the state had achieved compliance with the Community Consent Decree.

**Current System of Maine Services**

**T**he current service system includes agencies of federal and state government, private corporations, independent contractors, consumer groups, associations, and committees. There are different types of services available, including special education programs at the school. . Vocational centers teaching work skills. There are support programs providing services from transportation to activities to personal care. The range of services that is in place is impressive. Although funding and staffing are always in short supply, the range of services allows the person receiving services to live and be included in their community. This indicates quite a change in the past 20 years or less.

Appropriate housing is one of the most important services or needs. The goal is to provide each person with the appropriate level of support to enjoy a home that is safe, comfortable and specific to the person’s needs and preferences.

**Supported Living**

This is the most independent type of housing. People in this type of housing do most things for themselves. They may need some assistance for a few hours during the week for specific tasks such as shopping, transportation, doctor’s visits or meal preparation. An example of a supported living situation would be Dennis. Dennis works 40 hours per week at the local store as a stock clerk. He takes the bus to and from work. He is a diabetic and tests his own blood sugar. He gives his own insulin. He cleans his apartment, cooks his meals and does his laundry. Dennis needs help in shopping for foods that belong in his diet and figuring out his budget. Twice per week, Sue (a paid worker) goes to see Dennis. They figure out his menu for the next few days. She talks to him about his blood sugar levels. Then they go to the bank, do the shopping and pay the bills. All Dennis needs to be totally independent is Sue’s presence twice per week and a phone number to call if there is a problem.

**Shared Living**

In this type of arrangement the person receiving services has a housemate who is able to provide occasional assistance as needed. The housemate may receive reduced rent or a stipend to compensate for their assistance. Joan is a person receiving services.

Joan is very independent; she works during the day and pretty much manages her own life. Joan occasionally becomes afraid at night if she wakes up. She becomes confused and hysterical. Gladys has moved in with Joan. Gladys also works in the day. At night, Gladys is at home. If Joan gets up a bell rings to wake Gladys who then assists Joan. Gladys lives at the house rent-free for providing this service.

**Assisted Living**

Residential care or assisted living used to be called boarding care. These homes have rotating staff 7 days per week. The staff provides whatever assistance is needed. This may be training, transportation, recreation or personal care. These homes are licensed and inspected by the Department of Health and Human Services.

Bob lives in a home with Jack, Sam and Tony. They have staff on duty 24 hours per day. Staff helps Bob and his housemates cook the meals, clean the house and do the wash. They also all shop together. Bob needs help with bathing and dressing. Staff provides assistance with these tasks. Sam also needs the same help as Bob; in addition, he uses a wheelchair for mobility. Staff provides transfer assistance. The staff also administers all medications.

**Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)**

This level of care is for the most dependent people. Of course, housing and meals are provided. However, personal care, medication administration and nursing assistance are available. There are 2 types of these facilities depending on the number of clients and the degree of need. The first type is called “group” and is for people who do not need nurses 24 hours per day. These facilities house up to 8 people. The “nursing” type facilities may house up to 20 of the most physically dependent individuals with high levels of medical needs. These facilities have nurses always present.

Most people residing in ICF/IID are like Mary. Mary spends all of her time in a wheelchair due to her cerebral palsy. She eats using a feeding tube, which goes through her skin into her stomach. She is incontinent. She depends on staff for all of her physical needs. Furthermore, she chokes frequently and needs to be suctioned by a nurse. These facilities are inspected and licensed by the Department of Health and Human Services.

The type of living arrangements will depend on the needs of the person receiving services. In addition to living arrangements, most people require day services. Day service is a general term used for a variety of vocational, educational and social services.

**Vocational services** are focused on employment. They may include:

• Supported Employment provides on the job support for a worker with disabilities in a typical business setting where most employees have no disabilities.

• Job Search- services, which help to find jobs for people with limited work skills.

• Job Training – educational programs which teach the person employable skills.

**Community Supports** may include educational, social and therapeutic programs to help people develop their skills. There are various kinds of programs:

• Center based programs are provided at an agency site

• Community based programs support the person wherever the person goes in the community.

• Elder services offer a program at a more leisurely pace for the retired individuals.

• School programs are available for school age children. Each child in the state of Maine is entitled to a free and appropriate education.

**Case Management** is a planning service provided by both state and private agencies. Case managers help to plan and coordinate services, monitor the quality of services and advocate for services that may be needed. Case managers employed by the Department of Health and Human Services may also manage a person’s funds and act as the legal guardian.

**Government Involvement and Management of Services**

**T**he Maine Department of Health and Human Services (DHHS) is responsible for all human services provided to children and adults across the State of Maine. These include public health, mental health, substance abuse, developmental services, and services to children with behavioral or developmental disabilities.

The Department has many functions. The major functions include:

* Program development and funding
* Program regulations and policies
* Research and training
* Quality Improvement
* Licensing of programs
* Administering the Offices of Advocacy and Adult Protective Service
* Public guardian for some people
* Crisis Prevention and Intervention teams

There are other agencies of state and federal government that are involved in the provision of services but to a lesser extent. For example:

* OSHA: federal agency that provides workplace rules for employee safety
* Maine and U.S. Departments of Labor: wage and hour laws; child labor regulations
* Food and Drug Administration: regulations about pharmacy labels, food and drug packaging, etc.
* Maine Human Rights Commission: investigation of discrimination
* Bureau of Taxation: oversees payment of taxes; performs audits of businesses

A useful task for you would be to list all the federal and state laws and agencies involved in your agency. You will be surprised at how many there are. Many agencies and people work together to provide a spectrum of services to support the person as he/she lives a useful and happy life in community. This is a very different world then that experienced years ago by people with intellectual disability and autism. We have come a long way, but we have a long way to go.