Slide 1:
No Narration

Slide 2:
By the second half of the 20th century, new ideas in biological science, psychology, and human services had begun to redirect thinking about disability. Evidence of this can be found in the provisions of the education law that was enacted since the 1960s.

Slide 3:
Chapter 2 presents four influences that gained prominence during the later decades of the 20th century. These trends have had significant impact on medical, therapeutic, and educational treatment. As a result of these fundamental ideas, social expectations and opportunities for children with disabilities and their families have changed in significant ways. These four trends are:

- The theory that intelligence is “plastic” and can be changed by environmental influences
- Systems theories, which take social interactions as well as biological heredity into account
- A social model of disability, which reframes the nature of disability
- The normalization principle, which redefined objectives for human services

Slide 4:
This lesson discusses the normalization principle and its influence on treatment and opportunity for persons with disability and their families.

Slide 5:
In the decades after WW II, many state institutions became little more than human warehouses. The number of people committed to institutions increased while funding levels declined. The result was deplorable living conditions for thousands of residents who had been isolated and generally forgotten. But not by everyone. Undercover researchers Burton Blatt and Fred Kaplan photographed and documented conditions in four facilities in four different states. They reported that the institutions they investigated expended between $5 - $7 per capita per day to feed and house residents, who often went without adequate clothing, attention to personal needs, medical care, and programming. In 1966, Blatt and Kaplan’s expose, titled Christmas in Purgatory, was published and distributed to every member of Congress.

Slide 6:
Institutionalization of infants and young children with disabilities was prevalent. Doctors often counseled new mothers to institutionalize their babies with disabilities, and parents who did so expected that care and training appropriate to their child’s needs would be provided. However, many children died, not as a result of their disability, but due to inadequate care, unsanitary living conditions, and disease. Because of the remote locations of institutions, many families were unable to visit children regularly. Some parents never saw their children after they were placed. Few citizens were aware of the poor living conditions in state facilities. By the 1950s, many parents and others who did know had begun to organize for change. They demanded improvements to state facilities and the development of community resources to support families caring for children at home. (135)

Permission for photo – Infant behind crib bars. From Christmas In Purgatory: A Photographic Essay on Mental Retardation by Blatt, B. and Kaplan, F., 1966. Permission was granted on November 28, 2007 by Dr. Stephen Taylor, Co-Director, The Center on Human Policy, Law and Disability Studies, Syracuse University, School of Education

Slide 7:
In seeking to resolve the problems identified by concerned families and documented by Blatt and Kaplan, policy makers and program managers in the United States began to follow the lead of Denmark and Sweden. Those nations had
already addressed similar issues within their state-run institutions for persons with intellectual disabilities. Their reform efforts were based on a simple, guideline known as the normalization principle.

**Permission for photo** – A child restrained in chair. From *Christmas In Purgatory* by Blatt, B. and Kaplan, F., 1966. Permission was granted on November 28, 2007 by Dr. Stephen Taylor, Co-Director, The Center on Human Policy, law and Disability Studies, Syracuse University, School of Education.

**Slide 8:**
Normalization came to be viewed as a civil rights issue in Scandinavian countries. In 1959, the normalization principle had been written into the Danish law governing services for persons with mental disabilities. In 1968, a similar law in Sweden incorporated the normalization principle. Eventually the normalization principle was applied in federal regulation of services and programs for adults and children with any type of disability in the United States. The normalization principle applies to living, working and recreational aspects of life. It applies to children and adults regardless of the type or degree of disability condition. It applies to persons, regardless of whether they live in institutional settings or at home with their families (Ericsson, K, 1985; Nirje, B, 1969; Wolfensberger, 1972).

**Slide 9:**
The following examples illustrate normalization guidelines as they might apply to living conditions for young children with developmental delays and disabilities.

**Slide 10:**
Children experience regular patterns of activity such as getting up and getting ready for the day, participating in meals and snack times, and going to bed for naps and at night.

**Slide 11:**
Children are engaged in routine activities with their families and events in their communities. Examples might include household chores and leisure activities, visiting friends, shopping, and going to places like the library, the playground, the pool, the doctor’s office, or a parade.

**Slide 12:**
Children are included in the seasonal celebrations and activities of their family and community. For example children might share in birthday parties and holiday events, vacations, play in the snow or autumn leaves, and participate in gardening activities.

**Slide 13:**
To reach their full potential, all children need rich sensory experiences; appropriate materials, settings and activities; secure relationships with caregivers, and developmentally appropriate instruction.

**Slide 14:**
Normalization means that caregivers support the child’s growing sense of self, as well as his ability to initiate activities and to make and express personal choices.

**Slide 15:**
Normalization means that children are growing up in a world that is populated with both kinds of people – male and female.

**Slide 16:**
Normalization requires supplemental income programs to help ensure that children with disabilities and their families have a measure of economic security and a normal standard of living.

**Slide 17:**
Normalization means that children live in a home or home-like setting, within a neighborhood. They have access to the same standard of educational, recreational, and medical facilities as other children have.
Slide 18:
Perhaps no single concept has been a greater liberating influence on the lives of persons with disabilities than the normalization principle. On an international scale, normalization has provided a philosophical foundation for important legislation and adjudication supporting the rights of persons with disabilities. It continues to serve as a theoretical basis for research, administrative policy, and treatment practices.

Slide 19:
References:

Slide 20:
References:

Slide 21:
Resources:
- Disability is Natural
- Disability History Museum
  - http://www.disabilitymuseum.org/
- The Center on Human Policy, Law and Disability Studies
- Syracuse University
  - http://disabilitystudies.syr.edu/default.aspx
- The Life Span Institute
  - http://www.lsi.ku.edu/internal/guidelines.html

Slide 22:
Resources:
- The Self Direction Community Project Website:
- The Virtual Museum of Disability History
  - http://www.museumofdisability.org/
**EARLY INTERVENTION FOUNDATIONS**

**Chapter 2: Later 20th Century Influences on Treatment and Opportunity for Children with Disabilities**

**Lesson 4: Normalization Principle**

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**Later 20th Century Influences**

- Family Systems and Ecological Systems Theories
- Social model of disability
- Theory of plastic intelligence
- Treatment and Opportunity
- Normalization principle

**Institutionalized Neglect**

"**The ‘ISOLATE AND FORGET’ Principle Led To:**

- Underfunding
  - $5-$7 per capita per day for food and house residents
- Understaffing
- Poorly trained personnel
- Haphazard planning

**Segregation as Intervention**

- "Very young children, one and two years of age, were lying in cribs without interaction with any adult, without any playthings, without any apparent stimulation... we saw groups of 20 and 30 very young children lying, rocking, sleeping, sitting – alone." – Blatt & Kaplan, in Christmas in Purgatory, 1966

*"Inmates" was the term used to refer to humans such as these residents in a state institution.*

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Early Intervention Core Competency 1.0

Outcome: Early intervention personnel demonstrate an understanding of the theoretical, historical, philosophical, legal, and organizational components that provide the foundation for Part C of the Individuals with Disabilities Education Act (IDEA) and South Carolina’s BabyNet early intervention system.
“What can we do with those patients who do not conform? We must lock them up, or restrain them, or sedate them, or put fear into them.” – a frustrated attendant in a state-run institution, quoted in Christmas in Purgatory, by Blatt & Kaplan, 1966

The principle of normalization means…

“Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.” - Bengt Nirje, Director of the Swedish Association for Mentally Retarded Children

Routines for…

- getting up and getting dressed.
- bathing and grooming.
- eating meals.
- going to sleep.

Engagement in …

- family routines both inside and outside the home.
- community-based activities.
- indoor and outside play.
- public events and settings.

Participation in…

- holiday celebrations.
- family days of personal significance.
- seasonal activities.
- vacations.
**Normal Developmental Experiences of the Life Cycle**
- Access to …
  - rich sensory experiences.
  - settings and materials of proper proportions.
  - secure relationships with caregiving adults.
  - developmentally appropriate instruction and activities.

**Choices, Wishes and Demands Are Respected**
- Caregiver support for…
  - expression of likes and dislikes.
  - inclusion in activities with age peers.
  - personal choices.
  - communication about feelings.
  - initiation of activities.

**A Bisexual World**
- Interactions with…
  - family members, friends, and caregivers of both genders.

**A Normal Economic Standard**
- Opportunity for families to receive…
  - Compensatory economic security measures.

**Same Standards of Physical Facilities**
- Inclusion in…
  - a family home.
  - a neighborhood.
  - educational services in local schools and preschool programs.
  - a medical home.

**Summary**
- **Normalization Principle**
  - Make patterns and conditions of everyday life for persons with disability as close as possible to the social/cultural norms of the community.

- **Policy**
  - Identify normalization as a civil rights issue.
  - Incorporate normalization into law related to education, civil rights, and disability services.
  - Set normalization standards for service quality.

- **Effects**
  - Reduced numbers of children living in institutions.
  - Increased numbers of children living with families.
  - Increased participation in community activities.
  - Improved access to health and education programs.
References


Resources

- Disability is Natural
  [http://www.disabilityisnatural.com/peoplefirstlanguage.htm](http://www.disabilityisnatural.com/peoplefirstlanguage.htm)
- Disability History Museum
- The Center on Human Policy, Law and Disability Studies
  [http://disabilitystudies.syr.edu/default.aspx](http://disabilitystudies.syr.edu/default.aspx)
- The Life Span Institute
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- The Self Direction Community Project Website
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