Chapter 13: Very Low-Incidence Disabilities

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Focus Questions:

- **Very-low incidence disabilities** are typically severe in nature and require substantial and intensive accommodations, modifications, supports, instruction, and special education services. These disabilities include:
  - *Deaf-blindness*
  - *Multiple-severe disabilities*
  - *Traumatic brain injury (TBI)*

- Each very low-incidence disability has a separate definition, but share many similarities

**Very-low Incidence Disabilities: disabilities whose prevalence and incidence are very low**

**Deaf-blindness: A dual disability involving both vision and hearing problems**

**Multiple-severe Disabilities: Exceptionally challenging disabilities where more than one condition influences learning, independence, and the range of intensive and pervasive supports the individual and the family require; developmental disabilities**

**Traumatic Brain Injury (TBI): Head injury, causing reduced cognitive functioning, limited attention, and impulsivity**

**Historical Context**

- Helen Keller, arguably the most famous person with deaf-blindness, graduated from Radcliffe with honors in 1904
- Congress passed IDEA in 1975 to ensure education for students with disabilities. However, those with severe and very-low incidence disabilities had limited access to the general education curriculum
  - Today, students with severe and very-low incidence disabilities receive FAPE
    - IEP Teams consider this to be the most LRE possible
- In past years, adults with low-incidence disabilities were often segregated and forced to live away from cities and towns
  - Today, most children with severe disabilities are able to live at home with family members and in community apartments or group homes as adults
Challenges That Low-Incidence Disabilities Present

- Unique challenges occur to the individual and the family of those who have more than one major disability
- The more disabilities an individual has, the more difficult it becomes to find teachers who specialize in more than one area
  - Many individuals with severe disabilities are:
    - Sent to nursing homes and institutions
    - Receive minimal services
    - Afforded no education

Multiple-Severe Disabilities

Characteristics of Multiple-Severe Disabilities

- NICHCY (2004) explains some common characteristics of individuals with multiple-severe disabilities:
  - Problems transferring or generalizing learning from one situation to another, one setting to another, and one skill to another
  - Limited communication abilities
  - Difficulties with memory
  - Needs support for many of life’s major activities
    - Domestic
    - Leisure
    - Community
- Participation
  - Vocational
    - Needs services from many different related service providers

**Prevalence**

- 0.20%, or 132,846 of all American students ages 6 to 21, are considered having multiple-severe disabilities (according to the Office of Special Education Programs, 2008)
- Classification of individuals in one category or another tends to vary from state to state

**Causes and Prevention**

- Many factors can cause disabilities
  - Heredity
  - Problems during pregnancy
  - Problems are birth
  - Incidents after birth
- Advances in medical technology have now made it possible for children born with multiple-severe disabilities to have longer life expectancies
  - Many birth defects can be prevented with pre-pregnancy visits to the doctor

**Deaf-Blindness**

- One of the lowest incidence rates of all disabilities
- National Deaf-Blind Census revealed that more individuals with deaf-blindness have some functional use of their vision than hearing
- Special funding for students with deaf-blindness began in 1969

**Characteristics of Deaf-Blindness**

- Nearly half of all students with deaf-blindness are able to:
  - Read enlarged print
  - See sign language
  - move around in their environment
  - Recognize friends and family
- Some have sufficient hearing to understand some speech sounds
- Some have virtually no sense of vision nor hearing
- Many deaf-blind individuals also have other disabilities, such as intellectual disabilities
- Education is often so individualized and intensive that it does not occur in the general education setting
  - Only 9% of deaf-blind students (Around 503 nationally) attend general education classes for the majority of their school day
  - 82% attend
- Separate classes
- Specialized centers
- Hospital schools

- The combination of hearing and visual loss presents three characteristics for teachers and family members to consider
  - Feelings of isolation
    - Can be relieved through everyone becoming more “disability-sensitive”
  - Problems with communication
    - Some never learn to talk, making manual communication their primary means to express themselves
      - Sign language
        - Hand over hand
      - Body language
      - Gestures
  - Problems with mobility
    - Components of personal movement are instructional targets for many deaf-blind students
      - Becoming aware of one’s environment
      - Changing locations
      - Seeking protection from danger
      - Deciding when to move

Hand Over Hand: sign language for individuals with deaf-blindness where signs are conveyed through touch
Prevalence

- According to the National Deaf-Blind Census, some 7,985 students, ages 6 to 21, are identified as having deaf-blindness and also receive special education services
- According to the federal government (U.S. Department of Education), only 1,413 students were counted in this category
  - The different prevalence varies because the federal government wants states to report students’ disabilities in only one area
    - Problem: many deaf-blind students are in the “multiple disabilities” category

Causes and Prevention

- Prematurity and heredity
- Today, more than 50 genetic causes of deaf-blindness have been identified
  - Usher syndrome is a genetic cause that accounts for about 50% of all cases of deaf-blindness
    - Usher syndrome causes:
      - Deafness
      - Progressive blindness
      - Intellectual disabilities
    - Prevalence varies by location
      - In Louisiana, 15%-20% of students with deaf-blindness have Usher syndrome
      - Nationally, only 3% of students with deaf-blindness have Usher syndrome

Traumatic Brain Injury

- One million children, per year, experience a head injury
  - More than 30,000 of these injuries result in lifelong disabilities
- Advances in medical technologies have resulted in around 95% of children surviving head injuries
- Educator’s must know that TBI is not:
  - A condition which is present at birth
  - Caused by a stroke, brain tumor, or other internally-caused brain damage
- Educator’s must know that TBI is:
  - Due to a concussion or head injury
    - From an accident or child abuse
  - Not always apparent or visible
  - May or may not result in loss of consciousness

Characteristics of TBI
- Ranges in severity from mild to severe
- Brain injury often results with the following symptoms:
  - Dizziness
  - Headache
  - Selective attention problems
  - Irritability
  - Anxiety
  - Blurred vision
  - Insomnia
  - Fatigue
  - Motor difficulties
  - Language problems
  - Behavior problems
  - Cognitive and memory problems
- Students with TBI share similar learning characteristics as their classmates with learning disabilities:
  - Memory deficits
  - Attention problems
  - Language impairments
  - Reduced academic performance
- Many students with TBI benefit from instructional procedures that have been proven effective with students who have learning disabilities:
  - Direct or explicit instruction
  - Learning strategies
  - Structured school days
  - Organized classes with clearly specified expectation
- Some students experience seizures because of their head injuries and require many of the same accommodations as students with epilepsy
- Students with TBI and their families have to adjust to changes in:
  - Ability
  - Performance
  - Behavior

**Prevalence**

- According to the federal government, 23,864 students, ages 6 through 21, receive special education services because of TBI
  - Almost two-thirds of these students learn with classmates who are without disabilities

**Causes and Prevention**
- Half of all TBI cases are caused by “transportation accidents,” such as:
  - Car accidents
  - Motorcycle accidents
  - Bicycle accidents
- 20% are due to violence, such as:
  - Injury from firearms
  - Child abuse
- TBI injuries typically occur among teenage boys who:
  - Do not take safety precautions while bicycling, skiing, or skateboarding
  - Engage in high-risk behaviors such as driving too fast or mixing alcohol or drugs while driving
  - Participate in contact sports
- Shaken baby syndrome
- Many cases of TBI can be minimized and prevented
  - Wearing helmets when bicycling or skateboarding
  - Not driving a car or motorcycle when using intoxicating substances
  - Avoiding high-risk behaviors
Educational Considerations for Students with Low-Incidence Disabilities

Assessment:

Early Identification

- More and more children, birth through age 2, are receiving special services due to early identification of *developmental disabilities*
- Early identification is possible and has increased because of the medical and social services communities and awareness of signals for long-term developmental disabilities that have been well-documented

*Developmental Disabilities: severe disabilities including intellectual disabilities*

Prereferral

- Often, teachers who are alert are the first to suspect that an injury may have caused long-term problems
- Responsible actions to take before suggesting this to parents:
  - Seek advice from a school nurse
- Consult principal and maybe other school officials
- They MUST document student’s class performance
- Teachers who are more sensitive to their students’ performance may make a lasting long-term difference because they are able to bring quicker attention to problems and provide valid evidence of those problems to those who can help

Identification

- Students with multiple and coexisting disabilities are identified in very unique ways
  - Many are identified by doctors and nurses at birth
  - If they aren’t identified within the first six weeks of life, an alert pediatrician will typically identify those children who are not developing in typical ways
- The situation is different for students with TBI
  - Medical professional will usually identify students with TBI
  - However, sometimes a brain injury can go unnoticed by doctors or parents

Evaluation: Alternate Assessments- The “1% Kids”

- For students who do not participate fully in general education curriculum, the government allows the state to use alternate assessments
  
  **Alternate Assessments: a means of measuring the progress of students who do not participate in the general education curriculum**
  - These students are given alternate assessments on alternate achievement standards
  **Alternate Achievement Standards: fewer objectives or different expectations for achievement when participating in the general education curriculum**

- States are allowed to test up to 1% of students against the alternate achievement standards with alternate assessments

Early Intervention

- Early intervention for students with low-incident disabilities can determine critical outcomes:
  - Number and intensity of supports they will need as adults
  - Their attainment of independence
  - Level of community presence
  - Quality of life
- Five outcomes for families participating in services supported by the IDEA ’04 Families should:
  - Understand their child’s strengths, abilities, and special needs
  - Know their rights and advocate effectively for their children
  - Help their child develop and learn
  - Have support systems
  - Access desired services, programs, and activities in their community
- Benefits of inclusive early intervention programs are great in terms of:
  o Motor development
  o Language skills
  o Social interaction abilities
  o Academics

Teaching Students with Low-Incidence Disabilities

Access to the General Education Curriculum

- Students with low-incidence disabilities have less access to general education curriculum as their main objective
- Students with TBI have the highest participation rate in general education curriculum
  o Of those ages between ages of 6 and 21, 42% spend 79% of their school day in general education classes.
- Students with deaf-blindness have lower participation rates
  o 21% of them learn alongside of students without disabilities for 79% of their school day
- Students access the general education curriculum less for several reasons:
  o They require more intensive, individualized instruction
  o Their IEP goals focus on achieving adult independence and community presence
  o They participate in functional curriculum that includes direct instruction on targets such as daily living, vocational skills, and self-determination

Instructional Accommodations

- Making simple adjustments and modifications to a classroom routine can make a huge difference for children with low-incidence disabilities
- Some accommodations that might be made:
  o Adjust the order of presentation, having important subjects at the beginning of the day for students who are at school for the first part of the day
  o Have the most important academic topics at the start of the day
  o For students who have disabilities which effect their mobility, have an extra set of books for them in class and at home so they do not have to worry about carrying several books around
- Some students with deaf-blindness may need more intensive support
  o This can be provided most likely by a paraprofessional assigned full-time to one student

Data-Based Practices

- Different practices work for different students with different learning needs
- Story maps work well for helping students with TBI to learn organizing strategies

Story maps: simple diagrams used to organize and recall important elements and features of stories
- **Functional curriculum** is used to help students by providing instructional areas which connect to a person’s daily needs, it is not appropriate for every student with low-incidence disabilities
  - The IEP Team decides whether a student should access functional curriculum rather than focus solely on general education curriculum

**Functional Curriculum: instruction in natural settings relating to life and vocational skills**

- Before age 14, most vocational instruction occurs on the school campus
- After age 14, the labor laws allow students to work in the community
  - Functional curriculum moves away from the school at this point
  - This gives students with multiple disabilities opportunity to practice the skills they've learned in different settings
- This is accomplished through and is known as **community-based instruction (CBI)**

**Community-based Instruction: a strategy of teaching functional skills in the environments in which they occur**

- This is a proven practice that improves individuals’ inclusion in daily life as well as competitive employment when they are adults

**Technology**

- Technology helps these individuals:
  - Communicate more effectively
  - Increase their levels of independence
  - Control their environments
  - Have greater mobility
  - Gain access to information
- **Augmentative and alternative communication devices (AAC)** allows for communication and participation not otherwise possible for many individuals with multiple-severe disabilities

**Augmentative and Alternative Communication Devices (AAC): other methods for communicating, such as communication boards, communication books, sign language, and computerized voices**
Transition

Most students with low-incidence disabilities have a transition component of their IEPs.

These transition plans include:

- Employment
- Community participation
- Recreation and leisure
- Continuing education or services from state agencies
- Independent living
- Self-determination
- Quality of life
- Personal choice
- Opportunities for non-segregated work and living
Collaboration

Collaborating with Educational Specialists: Interveners

- In some cases, like in the case of students who are deaf-blind, students require special services
- An intervenor is a paraprofessional who works under the supervision of a teacher
  - They’re trained not only to translate but also to use sign-language
  - They provide instruction and facilitate all aspects of learning for the deaf-blind

*Intervener: a paraprofessional who serves many roles including sign language interpreter and teacher*

Collaborative Practices: The Role of the Intervener

- Interveners intercede and work between a child and the environment
- They help the child gain access to information that other children gain through vision and hearing
- They work on an individual basis with a student who is deaf-blind
- Facilitate inclusive efforts
- Another member of the collaborative team who is working with general educators to provide FAPE in the LRE
- They also help teachers by creating environments where learning can occur

Partnerships with Families and Communities

- In order for CBI to be successful, support from the community and businesses must be present
- The idea is to help individuals with significant needs for assistance and their families become independent and function in the community
- Family is one natural source of support for individuals with low-incidence disabilities
- Community agencies are also a huge help to these individuals
  - This is also an important reason why representatives should be involved in the development of transition components of these students’ IEPs
- Inter-agencies agreements are also encouraged to be established so the transition from school to adulthood includes supports that are necessary for community presence
- Goals include living in homes, apartments, and neighborhoods like everyone else

Summary

- Together, multiple-severe disabilities, deaf-blindness, and traumatic brain injury account for less than 1% of all school children
These disabilities, while composing a small percent, are still very severe and require resources and intensive individualized instruction