

Case 4: Intellectual and Developmental Disabilities

Learning objectives

- Define intellectual and developmental disabilities, explain their prevalence and causes, and outline the development of the intellectual and developmental disabilities field.
- Describe characteristics of individuals with intellectual and developmental disabilities.
- Explain how intellectual and developmental disabilities are identified.
- Describe recommended educational practices for students with intellectual and developmental disabilities.
- Explain the perspectives and concerns that parents and families of students with intellectual and developmental disabilities may have.

Case

Jack

Jack is nineteen years old, and he is a student at Lincoln High School. He attends classes for part of the day, and then he participates in a vocational training program. Jack takes part in one general education class, an art class that has only nine other students. He is assisted in the class by Ms. Russo, a special education paraprofessional. Jack has a moderate intellectual disability that is the result of a disorder called Fragile X syndrome, but his most significant challenges concern behavior. For example, he tends to be distracted by nearly any small noise or movement in the classroom. When he is upset, he sometimes chews on the neck band of his T-shirt. One thing that disturbs Jack is change in routine such as last week's shortened class schedule on an early-release day. Jack has just begun a new job. He is working two hours per day in the small business of a friend of his family, and his responsibilities include making copies, shredding documents, and helping to distribute and organize supplies. With the help of a job coach and this rather structured environment, Jack is quickly learning to work independently. Although Jack does not speak very often, he has communicated that he wants to work in a full-time job after high school. Jack's stepmother and father concur that Jack should work after high school, and they hope he can achieve his goal of living in an apartment. Even so, they are planning for him to live at home at least for the next few years, and they also are meeting with an estate planner to ensure that Jack has what he needs after they die.

Introduction

For most of the history of public schools, students with intellectual disabilities, also called *mental retardation*, have been characterized primarily by the word can't—what they can't do, what they can't learn, what they can't participate in. For example, in my own late-1970s classroom for students with mild intellectual disabilities, no books were provided because of the strongly held belief that these students could not learn to read. As these students became adults, the emphasis on their limitations continued. Except for those individuals who blended into society and shed their disability labels, most people with mental retardation lived with their parents, were placed in residential facilities, or resided under close supervision in group homes with several other adults with disabilities.

Although the past sometimes still influences professionals in today's schools, contemporary thinking about individuals with intellectual disabilities now is based on much higher expectations and a world of possibilities, not limitations. This has meant rethinking beliefs about these students' academic potential and the priorities they may have for their lives beyond the school years. As you learn from this topic, continue to think stigma associated with term mental retardation and reflecting on how your perceptions can influence these students' lives. How do the expectations you set and the enthusiasm you have assist students in reaching their goals?

What Are Intellectual and Developmental Disabilities?

Development of the Field of Intellectual Disabilities

The 1960s and 1970s were noteworthy for the growing emphasis on the rights of children with disabilities and the litigation that eventually formed the basis for Public Law (P. L.) 94-142, the federal special education law now called IDEA (the Individuals with Disabilities Education Act). It was also during this time that the definition of intellectual disabilities began to change. Most significantly, the approximate IQ cutoff score for being identified as having this disability was lowered from 85 to 70, thus changing significantly the number of students identified.

Even after federal special education law protected the basic rights of students with intellectual disabilities, their parents and other advocates continued to push for improved programs and services. Many of the first court cases addressing inclusive practices were brought by parents of students with intellectual disabilities. *Daniel R. R. v. State Board of Education* (1989) is considered to be the first critical test of inclusion (Yell, 2006); it concerned a student with Down syndrome. In this case Daniel's parents filed suit because their son had been removed from a general education prekindergarten class because of his highly disruptive behavior. The Fifth Circuit Court of Appeals ruled that Daniel's needs were so great that he could not be educated with his peers and that Daniel had sufficient contact with his peers in nonacademic activities.

In *Sacramento City Unified School District v. Rachael H.* (1994), the Ninth Circuit Court of Appeals reached a different decision (Yell, 2006). Rachael, a student with a moderate intellectual disability, had been educated in special education classes for several years, and her parent requested a general education placement. The school district refused, arguing that Rachael's needs were too significant. The court found that the school district had not demonstrated that Rachael could not be instructed in a general education setting and supported Rachael's parents' request for a more inclusive education.

Definitions of Intellectual Disabilities

The term used in IDEA is mental retardation, and many (but not all) states still use it. However, this term often is considered offensive and stigmatizing, partly because of the negative connotations assigned to it at the beginning of the twentieth century (Akrami, Ekehammar, Claesson, & Sonnander, 2006; Cuskelly, 2004). Many professionals and parents now use the term intellectual disabilities. In fact, in January 2007 the American Association on Mental Retardation (AAMR), the leading professional organization addressing the needs of these individuals throughout the life span, changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD).

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You may find that your state uses yet other terms to refer to students with intellectual disabilities. For example, you may hear the term cognitive impairment or cognitive disability or mental impairment or mental disability. What are the terms used in your state to describe this group of students? Which terms do you think have the greatest and least stigma associated with them?

Federal Definition

Mental retardation is significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.

American Association on Intellectual and Developmental Disabilities Definition

The following five assumptions are essential to the application of this definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed support.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.
(Luckasson et al., 2002, p. 1)

Prevalence of Intellectual Disabilities

Because the decision to identify an individual as having an intellectual disability involves professional judgment, no single prevalence estimate is considered definitive. For example, the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002) estimates that 2.5 percent of the population has this disability. The Arc (2004), an organization for professionals and parents supporting children and adults with intellectual disabilities, estimates prevalence at 3 percent. These data suggest that school-age children with intellectual disabilities are underidentified.

Causes of Mental Retardation

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A mild intellectual disability for which a specific cause cannot be identified is sometimes referred to as cultural familial retardation. This term is a remnant of early-twentieth-century thinking in that it implies that intellectual disabilities occur in certain family groups and are related to the ways in which they live.

For students with more significant intellectual disabilities, the causes usually are considered in terms of when they occurred: during the prenatal period (e.g., Down syndrome, Fragile X Syndrome, Prader-Willi syndrome, fetal alcohol syndrome, and Phenylketonuria, Toxoplasmosis), the perinatal period (e.g., lack of oxygen), or the postnatal period (e.g., encephalitis, lead poisoning, and brain injury).

What Are the Characteristics of Individuals with Intellectual and Developmental Disabilities?

Cognitive and Academic Characteristics

A student is identified as having mental retardation only if his IQ score places him at approximately two standard deviations or more below the mean or average score of 100. And even though IDEA does not draw these distinctions, in tradition classification systems individuals are grouped based on the extent of their cognitive impairment:

Mild mental retardation: IQ=55-69

Moderate mental retardation: IQ=40-54

Severe mental retardation: IQ=25-39

Profound mental retardation: IQ=below 25

The cognitive characteristics of students with intellectual disabilities have a significant impact on several dimensions of cognitive functioning (Bergeron & Floyd, 2006), including memory, generalization, metacognition, motivation, language, and academic skills.

Social, Behavior, and Emotional Characteristics

Many students with intellectual disabilities have difficulties in social relationships (Addeduto et al., 2006). First, many students with intellectual disabilities have immature behaviors that make other students want to avoid them. Second, their ways of dealing with social situations may be inappropriate (Farmer, 2000). For instance, a student with an intellectual disability may walk up to a group of students engaged in conversation and elbow his way in; those students then may form a negative perception of him. Finally, students with intellectual disabilities may have difficulty picking up subtle social cues, and so they may misinterpret other students' actions (Leffert, Siperstein, & Millikan, 2000). One way that school professionals measure the social relationships among students in their classrooms, including those with intellectual disabilities, is to use sociograms as explained in the positive Behavior Supports.

In addition, researchers have found that students with intellectual disabilities experience more loneliness than students without disabilities but that these differences diminished as students entered adolescence (Heiman & Margalit, 1998). Clearly, valuing individuals with intellectual disabilities includes understanding that they experience the same emotions as others and that they have mental health needs (U.S. Department of Health and Human Services, 2001; Lorenzi, Horvat, & Pellegrini, 2000).

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How Are Intellectual and Developmental Disabilities Identified?

For students with intellectual disabilities to receive special education services, they must go through the formal process of identification. For some students, this will have occurred when they are very young, even as infants, using assessment methods designed just for that age group. Other students are identified when they enter kindergarten and cannot manage the academic, social, and other expectations of the school setting, and yet others are identified sometime during the elementary school years.

It is important to note that no single test can measure all aspects of intelligence. Moreover, intelligence tests tend to ignore what some people consider key components of intelligence, such as creativity and humor.

Eligibility

1. Does the student's intelligence, as measured on a formal individual assessment, fall at least 2 standard deviations below the mean? That is, is the student's measured IQ approximately 70 or below?
2. Does the student display deficits in adaptive behavior?
3. Do the student's characteristics adversely affect educational performance?

What Are Recommended Educational Practices for Students with Intellectual and Developmental Disabilities?

A number of instructional strategies that are effective for teaching students with intellectual disabilities, such as planning for generalization and making abstract concepts more concrete. In addition, direct instruction and behavior interventions such as clear rules, schoolwide behavior plans, and the use of contracts are recommended. Furthermore, task analysis (i.e., to break any task or activity into small step) and peer-mediated instructions (i.e., peer tutoring) are also often applied in educating students with intellectual and developmental disabilities.

What Are the Perspectives of Parents and Families?

Although nearly all parents want their children with intellectual disabilities to have a normal life (Harry, Rueda, & Kalyanpur, 1999), the meaning of normal differs for families based on several factors. One important consideration is the extent of the child's cognitive impairment. Children with mild impairments may be similar enough to their siblings that parents adjust their expectations but do not have extraordinary concerns (Hannah & Midlarsky, 2005). However, parents may have many questions about their children with moderate or severe intellectual disabilities. Another factor affecting parents' concerns is age: Parents of young and school-age children are likely to worry about developmental and medical issues as well as behavior problems (Baroff & Olley, 1999). Parents of adolescents express concern about those problems, too, but they also begin thinking about what their child will do and how their child will live after graduation. As the parents of children with intellectual disabilities themselves face aging, they become concerned with the possibility of keeping an adult child at home, the need to arrange for someone to look after their child after they die, and the necessity of providing for the child financially (Lustig & Akey, 1999; Thorp, 2002).

You should remember that whatever type of service you provide—whether general education, special education, or a related service—your goal is to base your work on the priorities of the students and families, even when they are not consistent with your own.

Back to the Case

Jack

Jack's transition from school to the adult world is under way. His parents are engaged in planning for his future after they have died, and his job coach is helping Jack meet his goal for employment. However, Jack continues to experience difficulty with behavior and interpersonal relationships at school. Both of these issues may have a negative effect on his successful transition into the work world. What role should school personnel take to help Jack?

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