

Down Syndrome

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Introduction

Down syndrome is a genetic condition that causes delays in physical and intellectual development. According to the National Down Syndrome Society, it occurs in one out of every 733 live births (*Information Topics*, 2006, para. 3). Named after John Langdon Down, the British doctor who first accurately described it in 1866, individuals with Down syndrome have 47 chromosomes instead of the 46 non-Downs individuals have. The National Association for Down Syndrome states it is “usually caused by an error in cell division called nondisjunction” (n.d., p. 1) that involves the 21st chromosome and this error occurs at conception. While it is not related to anything the mother did during pregnancy, the incidence of Down syndrome increases with advancing maternal age.

Down syndrome is one of the causes of mental retardation, defined by the American Association on Mental Retardation as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills” which manifests before the age of 18 (*Definition*, n.d., para. 5). Individuals with Down syndrome are usually in the mild to moderate ranges of mental retardation, with IQ scores between 35 and 69.

Individuals with Down syndrome have 54 traits that make them unique. Some common physical features and characteristics of Down syndrome include low muscle tone, a simian crease (a single crease across one or both palms), an upward slant of the eyes, a flat nasal bridge, shorter limbs, speech impairment, and a protruding tongue. Children with Down syndrome face a number of health complications. According to the NADS (n.d.), “approximately 40% of the children [with Down syndrome] have congenital heart defects” and they also have “a higher incidence of infection, respiratory, vision and hearing problems as well as thyroid and other medical conditions” (p. 1). Although some individuals with Down syndrome live into their sixties and seventies, the average life expectancy is 55 years.

Historical Look at the Schooling of Individuals with Down Syndrome

Throughout history, individuals born with physical or mental impairments were thought to be less human and a burden on their families and the larger community. They were banished, confined, alienated; during the medieval times, for example, individuals with an “unreasonable mind” were put on ships and “set adrift on the sea” (Kliewer, 1998, p. 20).

Before the 19th century, there is little evidence of the existence of individuals with Down syndrome. It is likely they were categorized as cretins, considered a burden on the community and banished (meaning confined). Kliewer (1998) wrote, “Confinement occurred in decrepit institutions based on the abstract justification that those so banished were animals, a lower species in relation to humanity” (p. 26). In the mid-1800s, written accounts describing characteristics of Down syndrome emerged; Robert Chambers referred to a “Mongolian type—that is, persons who in maturity still are a kind of children” (p. 22) and John Langdon Down was the first to publish an accurate description of a person with Down syndrome, using the terms “mongolism” and “mongolian idiocy” (*Down syndrome*, n.d., para. 31). (It wasn’t until 1959 that French doctor Jerome Lejeune discovered the 47th chromosome.)

Throughout the 19th century, confinement of individuals with Down syndrome remained the popular choice, but there were some, who, influenced by the Enlightenment, began to think otherwise. Edward Sequin, for example, brought to the United States the idea that individuals with disabilities were educable and could be taught useful skills needed to perform necessary community tasks; unfortunately, his use of a central location in which to educate these individuals inadvertently resulted in the “emergence and proliferation of institutions” (Kliewer, 1998, p. 28). At the end of the 19th century, “in conjunction with the developing eugenics movement and compulsory school attendance laws” (p. 31), segregated classrooms formed for “slow and backward” students, but children with

Down syndrome were automatically excluded from educational opportunities because it was presumed they could not learn. Instead, they were either cared for by their families or sent to institutions.

It wasn't until after World War II that parents began organizing a movement for educational opportunities for their children with significant disabilities, including Down syndrome. Although more special education opportunities emerged, and in 1949, Dr. Benjamin Spock voiced support to raise children with disabilities at home and educate them in appropriate programs, this still excluded children with Down syndrome. Spock instead "advised parents of newborn mongoloid infants to immediately institutionalize them, explaining that the child would 'exist at a level that is hardly human,' thereby wrenching apart the social fabric of the family" (p. 36).

With time, the causes of Down syndrome were discovered and the educability of individuals with Down syndrome was reconsidered. In the 1960s, inspired by the civil rights movement, disability professionals joined with the parents in their advocacy. As stated by Kliever (1998), these "advocates exposed the horrific conditions maintained in state institutions" as well as worked to "develop community-based living options" for individuals with disabilities. Disability rights attorneys declared that a disability did not "void an individuals' right to protection guaranteed by the Constitution, including the Fourteenth Amendment," and battled forced institutionalization by coining the phrase least restrictive environment (p. 40).

The Education for All Handicapped Children Act was passed in 1975 (renamed the Individuals with Disabilities Education Act in 1990), ensuring that all children with disabilities received a free and appropriate education in the least restrictive environment. This was a huge step for individuals with Down syndrome. Although some professionals still believed the education of children with Down syndrome was a waste of resources, and that schooling would have little impact on them, children with Down syndrome became students in special education classrooms in public schools. Research in the

late 70s and early 80s found that “large numbers of children with Down syndrome had the potential to benefit from schooling in academic content areas” (p. 42) and it described in detail the children’s development in writing skills, reading comprehension and problem solving abilities.

The mainstreaming movement of the 1980s promoted including special education children in regular education classrooms. Differentiating inclusion from mainstreaming, the NDSS states, “Mainstreaming implies that a student from a separate special education class visits the regular classroom for specific, usually non-academic, subjects. Inclusion is an educational process by which all students, including those with disabilities, are educated together for the majority of the school day” (*Inclusion*, n.d., para. 2). In recent years, mainstreaming has given way to the concept of inclusion, which remains a controversial issue.

Inclusion

According to the NADS, most children with Down syndrome “attend their neighborhood schools, some in regular classes and others in special education classes.” Some children, however, “have more significant needs and require a more specialized education” (n.d., p. 2). Students with Down syndrome who attend public schools may be taught either in a self-contained special education classroom or in a regular education classroom, with pull-out services or related services, such as having a paraprofessional.

On one side of the inclusion debate, research has found that inclusion of students with disabilities in regular education classrooms benefits both the students with disabilities and their non-disabled classmates. For instance, a 1995 study of inclusive education conducted by the National Center on Educational Restructuring and Inclusion reported “academic, behavioral and social benefits

for students with and without disabilities” (para. 28). In regards to students with Down syndrome, in particular, a 1996 NDSS report found:

“that with proper support and adequate communication between parents, teachers and professionals, inclusion is a favorable educational placement for children with Down syndrome. The study also found that the learning characteristics of students with special needs were more similar to their nondisabled peers than they were different. Moreover, teachers reported positive experiences with students with Down syndrome. They described their students as eager to learn, especially when encouraged, and reported personal satisfaction in terms of their professional achievements” (para. 27).

On the other side of the inclusion debate, however, there are justifications for keeping students with Down syndrome out of the regular education classroom. According to a Wikipedia article,

“Children with Down syndrome do not age emotionally/socially and intellectually at the same rates as children without Down syndrome, so eventually the intellectual and emotional gap between children with and without Down syndrome widens. Complex thinking as required in sciences but also in history, the arts, and other subjects is often beyond their abilities, or achieved much later than in most children. Therefore, if they are to benefit from mainstreaming without feeling inferior most of the time, special adjustments must be made to the curriculum” (*Down syndrome*, n.d., para. 21).

What is important to remember is that each child with Down syndrome is an individual, with a wide range of strengths and weaknesses. Not all children with Down syndrome, therefore, can or will excel and/or benefit in a regular education classroom. This is where IDEA fits into the equation.

“The starting point in any discussion of where a student should be educated is the age-appropriate general education classroom in the school that the student would attend if not disabled. However, it is important to remember that this placement is not necessarily appropriate for every student. Full inclusion may not be every individual’s least restrictive environment. For some, LRE may be full inclusion in a general education classroom with supplementary support such as a special education teacher aide, or paraprofessional. For others, LRE may involve a self-contained classroom comprised of all students with disabilities. Therefore, the least restrictive environment may be different for each student, depending on his or her individual needs. It is important to note that IDEA clearly specifies that the placement of any student must be based upon the individual’s identifiable needs, not based on the student’s diagnosed condition or categorical label”

(Inclusion, n.d., para. 15-16).

Development, Learning, and Educational Accommodations/Modifications

For those students with Down syndrome who do spend the majority of their school day in a regular education class, there are numerous accommodations, modifications and assistive technology

that can be implemented. Research focused on the development of children with Down syndrome has helped to create rationales for such procedures.

The cognitive development in children with Down syndrome varies and it is not possible at birth to predict their capabilities. The cognitive problems that are found among children with Down syndrome can also be found among typical children. Many can be successful in school, while others struggle. Children with Down syndrome, however, “show the greatest delays in motor and language development” (Krajicek et al, 2004, p. 105).

As far as language development, although they may understand speech and language, children with Down syndrome may have difficulty verbally expressing themselves. This is due in part because of their large tongue in a smaller oral cavity and poor muscle tone. It is common for children with Down syndrome to need speech therapy to help with expressive language. Some have advocated the use of sign language to help children with Down syndrome learn how to talk. Hopmann (1993) advises the use of Total Communication, in which “individuals are encouraged to use oral language and other means (sign language, gestures, signs, pictures, writing) to communicate as fully as possible what is on their minds, and understand what others are communicating” (p. 22).

Klein et al (2001) suggests slowing down the pace of classroom instruction and activities when a student with Down syndrome seems to be having difficulty grasping the information or learning a routine. It is important to note that pacing “involves both the rate of speaking and moving—how fast the teacher talks or performs a task or activity—as well as how long the teacher waits for the child to respond or complete a task” (p. 26). In addition to increasing “wait time,” teachers must also curb the desire to finish a child’s thought or correct their pronunciation while the child is still speaking. “Sometimes children need additional thinking time and word retrieval time. If they learn that someone will finish their thoughts, speak for them, or correct them all of the time, they will lose the motivation to

speak” (Nobis, n.d., para. 5). To also help students with Down syndrome with their language and speech, teachers should enunciate words clearly, use inflection liberally and point out their own mistakes when speaking.

Although not as obvious as speech and language difficulties to notice in the early years, children with Down syndrome have a delayed development of fine motor skills, which often lag behind gross motor skills. This is due to low muscle tone. According to Bruni (1998), the impact of such delay can be significant.

“The ability to use their hands directly determines the amount of assistance our children need to accomplish the many daily activities of home, school, work and leisure. The more assistance they need, the less independent they can be, and the fewer choices they may have for their futures” (p. xiv).

Students with Down syndrome often have difficulty with writing skills. The low muscle tone in their lower arms and hands make “it difficult for the child to position his finger joints to hold an object such as a pencil without his joints ‘collapsing’” (p. 14). Lorenz (1998) suggests a number of strategies, including: encouraging children to experiment and become comfortable with a wide range of drawing and writing materials while making writing activities both fun and meaningful; allowing children to “write” their names at the top of papers as their peers do, even if it begins as a scribble; and using visual aids to encourage correct pencil grip, “e.g. drawing a dog on the child’s hand between the thumb and first finger, to be stroked by the child’s pencil during writing” (p. 51). Low-tech assistive technology can also help with the proper grip of writing implements. For example,

“triangular pencils may be easier for the child to manipulate and felt tips may flow more easily than pencils. Some children are helped by

pencil grips or by an elastic band wound round the pencil to indicate where it should be held” (pp. 51-52).

Lorenz states that if a child is reluctant to use a pencil, using a multisensory technique, such as having the child write in sand or shaving cream, is an acceptable way for the child to begin writing.

Klein et al (2001) states that although children with Down syndrome “achieve many of the same developmental milestones as typically developing children,” they usually “do so at a slower pace” (p. 25). Also, their response rate is often slow and they will need many repetitions to master a task. In addition, children with Down syndrome often exhibit low task persistence. “That is, they are not motivated by the challenge of a difficult or lengthy task. They are more likely to be motivated by the praise and encouragement of their significant others, rather than by task mastery and achievement” (p. 26). For behavior management strategies, Wolcott (2001) found that praise, again, was reported as the best option for students with Down syndrome. “Material rewards, time out, peer pressure, loss of privilege, and teacher contact with parents were reported as sometimes helpful,” but “ignoring, reprimands and punishment were not effective at all, possibly because of the student with Down syndrome’s inability to link these consequences with their inappropriate behavior” (p. 5).

Research has also shown that children with Down syndrome are usually visual learners. Their auditory memory—remembering what they hear—is not as strong and so they learn better when “information and skills are taught visually, or with a combination of visual and auditory presentation” (Bruni, 1998, p. 7). Placing number and alphabet lines on their desks as well as using diagrams to go over directions can also help students with Down syndrome learn more effectively.

Wolpert (2001) found that the best learning arrangement for students with Down syndrome was 1:1 instruction and small group instruction. “Peer tutors, computers and team teaching were found to be sometimes effective,” but “large groups and whole class lessons were reported not effective at all”

(p. 4). The most effective instruction occurred at or near the student's desk and teachers reported that "hands-on" or "real" materials were most effective with students with Down syndrome. While computers, paper and pencil tasks and textbooks were "sometimes effective (only in the upper grades)," workbooks were not useful (p. 4).

Conclusion

Down syndrome is a disability that affects many aspects of an individual's life and we cannot predict how exactly the 47th chromosome will impact each individual's learning and development. We do know, however, that individuals with Down syndrome can learn and can succeed in educational settings. The resources on accommodations, modifications and assistive technology available for students with Down syndrome are immense and accessible. With this knowledge, teachers who have students with Down syndrome in their classrooms have ample opportunity to make a difference in these children's lives.

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