Vol. 9, No. 1, 2018
DOI: 10.14746/jgp.2018.9.002

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Supporting boys and girls with Down syndrome

ABSTRACT. This paper will address students who have the diagnosis of Down syndrome. It will encompass the overall understanding of what a child with Down syndrome experiences in and outside of the classroom, as well as some of the physical characteristics that can manifest as a result of a genetic mutation resulting in the diagnosis of Down syndrome.

KEYWORDS: Down syndrome, genetic mutation, school, education

Introduction

This paper will address students who have the diagnosis of Down syndrome. It will encompass the overall understanding of what a child with Down syndrome experiences in and outside of the classroom, as well as some of the physical characteristics that can manifest as a result of a genetic mutation resulting in the diagnosis of Down syndrome. According to the United States National Library of Medicine, in current times, community members now refer to Down syndrome as an intellectual disability (*Down syndrome—Genetics Home Reference,* n.d. para. 1) even though in the past people with the condition used to be referred to as mentally retarded or mentally handicapped. Down syndrome is a chromosomal condition which means that it occurs on a genetic level and is a result of a genetic mutation (*Down syndrome—Genetics Home Reference,* n.d. para. 1). The parents of an individual with Down syndrome do not typically have Down syndrome and it occurs by random chance. Down syndrome is a very common genetic disorder and it occurs in about 1 per 1000 babies born each year (*Clinical practice*, p. 169). There is currently no cure for Down syndrome, but education and proper care can improve a student's quality of life (*Down Syndrome: Other FAQ's.*).

Down syndrome (DS) occurs when an individual has an extra full or a partial copy of chromosome number twenty-one in all of the body's cells (*Down Syndrome—Topic Overview*, n.d. para. 2). In other words, DS occurs when the cells have three copies of chromosome 21, which is why DS is known as Trisomy 21. Typically, the nucleus of each cell within the human body contains twenty-three pairs of chromosomes, for a total of forty-six chromosomes (*Down Syndrome—Topic Overview*, n.d. para. 2). With the added copy of chromosome number twenty-one, the additional genetic material alters the course of development and causes the characteristics of DS to be expressed (*Down Syndrome—Topic Overview*, n.d. para. 3).

There are three variations/degrees of Down syndrome: Trisomy 21, known as nondisjunction, translocation and mosaicism (*What is Down Syndrome*, n.d. para. 7). Trisomy 21 is caused by an error in cell division prior to or directly at conception (*What is Down Syndrome*, n.d. para. 8). A pair of the 21st chromosome in either the sperm or the egg fails to separate, which results in an extra copy being replicated in every cell of the body (*What is Down Syndrome*, n.d. para. 8). This type of Down Syndrome accounts for ninety five percent of the cases (*What is Down Syndrome*, n.d. para. 9). The second variation, known as Translocation, only accounts for four percent of the cases of Down syndrome (*What is Down Syndrome*, n.d. para. 13). This occurs when an additional full or partial copy of chromosome twenty-one attaches to chromosome fourteen. The remaining one percent of cases (Mosaicism) occurs when there is a mixture of cells, some containing the usual forty-six chromosomes and some of them containing forty-seven chromosomes. Most of the individuals with this expression of DS usually show fewer characteristics of it.

The characteristics of Down syndrome include low muscle tone, un upward slant of the eyes, a small stature or a single deep crease across the center of the palm and an overall IQ ranging from 30–60 (Normal Range 90–110), (*Down Syndrome—Topic Overview*, n.d. para. 3 & 4). People with DS can also have a variety of birth defects. Roughly half of children born with DS are born with a heart defect, while digestive abnormalities such as blockage of the intestines can also occur (*What is Down Syndrome*, n.d. para 10–13). Most individuals with DS have an increased risk of several medical conditions which include gastroesophageal reflux, which is known as a backflow of acidic stomach contents into the esophagus, as well as celiac disease, which is an intolerance of a wheat protein called gluten (*Down Syndrome—Genetics Home Reference*, n.d. para 3). About fifteen percent of people with DS have an underactive thyroid gland known as hypothyroidism (*Down Syndrome—Genetics Home Reference*, n.d. para 4).

Students with Down syndrome often have many learning challenges that extends to many areas of development and the students typically fall behind the normal rate of progression compared to their typical peers. Due to these challenges, teachers can implement some creative accommodations to help children with DS to still be successful while at school. Often boys and girls with DS develop at a slower rate of motor development which limit student's with DS opportunities to explore and learn about the world around them at an early age. According to the Cork Special Education Department, the best way to address this concern is to have teachers "use many manipulatives and tactile demonstrations that allow students with Down syndrome to interact with their peers" (*Special Education Support Services*, 2017). Without these interventions, it could affect their overall cognitive ability and contribute to an inability to speak at a young age, which could lead to poor oral motor control later in life (*Special Education Support Services*, 2017). Boys and girls with DS have also have specific delays in learning to use spoken language relative to their nonverbal understanding (*Special Education Support Services*, 2017). Often students with DS struggle in learning sentence structures and grammar and developing clear speech pronunciation. Small group instruction and by implementing Think, Pair, Share sessions into a classroom can help students develop an understanding of spoken language because both strategies encourage students to work together with their peers and problem solve. Both strategies can contribute to students to have a better understanding of what they are reading and can help develop an overall deeper comprehension of the material by encouraging opportunities to students to speak to one another while in the classroom.

Boys and girls with DS also struggle mastering basic number skills and often fall two grade levels behind their peers (*Special Education Support Services*, 2017). Using Direct Instruction and using clear and concise language is the most effective way to develop fundamental math skills necessary for students to advance later in their academic journey. Overall, many of the educational struggles with boys and girls with Down syndrome stem from the main concern they often have limited short term memory which limits a student's ability to process and learn spoken language and remember concepts already taught. This is addressed by the teacher establishing routines and by consistently repeating and re-teaching instruction to boys and girls with Down syndrome so they have the best chance of remembering what they learned so they can build upon prior knowledge. An effective strategy would be to have an introduction activity each class period that requires students to recall what they did the previous class period.

The way that Down syndrome affects learning in the community and a workplace is a complex issue because a person's unique experience is closely tied to the way that community members themselves respond to a person having a "disability" and by how prepared the person with DS took the time to create a well-developed transition plan and by what steps they have taken to be as independent as possible post high school. According to the National Down Syndrome Society (NDSS), a "well-developed transition plan includes vocational skills, postsecondary options and future employment (*National Down Syndrome Society*, 2017). Vocational skills would include how to get to a from work, how to work cooperatively with others, how to follow directions, how to use public transportation, shop for groceries etc." (*National Down Syndrome Society*, 2017). Postsecondary options and future employment would be determined by a case by case basis based on the child's unique gifts and talents.

In regards to future housing, there are four main options for boys and girls with DS. They include a student choosing to remain living at home with their parents, a student choosing to live in a dorm, a student choosing to live in a supported environment and receive the necessary services or a student can live in a group home environment. (*National Down Syndrome Society*, 2017). These options should be discussed with the students and their parents at individual meetings and should not be a surprise when a student completes secondary school.

Regarding future employment, there are three main types of employment for boys and girls with DS according to the National Down Syndrome Society which include competitive employment, supported employment or a sheltered employment (*National Down Syndrome Society*, 2017). A competitive employment is essentially the open job market in which the student with DS would be working independently and receiving no supports/accommodations. A more common environment is a sheltered job in which an individual with DS receives support services while on site or a job coach is available to teach the boy or girl until the individual can complete the job on his/her own. (*National Down Syndrome Society*, 2017). The final option is known as a sheltered environment in which boys and girls can work in a self-contained area with other individuals with disabilities without the integration of non-disabled workers (*National Down Syndrome Society*, 2017). Similar to student living, these options should be discussed with the students and their parents at individual meetings.

Three strategies for supporting interactions between students with Down syndrome and their typical peers would be the educational placements of full inclusion or mainstreaming classes, while also mainstreaming sports/extracurricular activities outside the classroom. According to Dr. Vandergriff from Knox University, the main difference between full inclusion and mainstreaming classes is that full inclusion "would eliminate all pull out and self-contained classes and students with disabilities would be fully integrated into the General Education curriculum." (Vandergriff, 2008). This essentially means that students with Down syndrome would be taught fully alongside their general education peers without the need of separation. Mainstreaming classes is essentially the idea that "students with special needs would be mixed between special education self-contained classrooms and a regular classroom through the school day". Both of these options allow students to communicate with their typical peers and allow them a chance to learn alongside their typical peers. The typical peers would be able to learn more about the child with DS, rather than judging them based on their physical characteristics of Down syndrome. Mainstreamed sports/extracurricular activities would also allow students with DS to bond with their typical peers beyond the confines of an educational space and to develop healthy social connections.

Three resources or strategies for sharing information about boys and girls with Down syndrome with their typical peers would be introducing typical boys and girls to the Best Buddies International Program, providing books on Down syndrome to typical students, and incorporating educational videos from people with Down syndrome who can share their own life experiences within the classroom curriculum.

According to their own website, The Best Buddies Program "is an international nonprofit organization dedicated to establishing a global volunteer movement that creates opportunities for one to one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities." (*Best Buddies*, 2017) The Best Buddies program allows "typical peers" the best opportunity to fully engage socially with students with disabilities while allowing each student to learn about each other in a safe and appropriate space. When a teacher can incorporate videos or provide books for typical peers to learn more about Down syndrome, it engages general education students to become more curious about students with DS. Essentially, the recognition that students with disabilities are present at school and are incorporated into the curriculum could lead to typical students to have less criticism to students with disabilities because they will be armed with knowledge about the condition rather than be afraid of students with disabilities.

Four resources for sharing information about individuals with Down syndrome with parents or other professionals would be the following: (1) reviewing the IDEA (Individual Disabilities Education Act) and their Parental Rights through the website (http://www.parentcenterhub.org/categories/), (2) introducing parents to the National Down Syndrome Society website (http://www.ndss.org), (3) introducing parents to the Down Syndrome Research and Treatment Foundation (http://www.dsrf.org) and (4) *Down Syndrome Parenting 101: Must Have Advice for Making Your Life Easier*. Understanding the IDEA and parental rights will allow them to truly understand what services parents are entitled under the law and how to find the best resources for their children. According to the website, The National Down Syndrome Society is "the leading human rights organization for all individuals with Down syndrome" (*National Down Syndrome Society*, 2017). The website provides webinars to parents about how to best prepare for having a baby born with Down syndrome and provides a variety of local and national resources that parents can access free of charge. The Down Syndrome Research and Treatment Foundation provides the most updated research that is being conducted about treating Down syndrome while the book "Down Syndrome Parenting 101: Must Have Advice for Making Your Life Easier" provides an all-encompassing Step by Step guide about how to be the best resource and parent for a child with Down syndrome.

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