

The Innovation of Down Syndrome Inclusion

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Inclusion of Down Syndrome Students in Education

When one is asked to examine and critique an innovation a history of how the innovation came to be would be necessary in order to determine the worthiness of the change. “To understand the battles being fought today for children with disabilities, it is important to understand the history and traditions associated with public schools and special education,” (Wright & Wright, 2007) Michael Fullan stated, “Putting ideas into practice was a far more complex process than people realized,” (2007). The practice of inclusive education, specifically inclusion of Down syndrome students, is a complex process that has been reformed and redefined over many years. These changes have formed the Down syndrome inclusion in schools today.

Special education programs did exist in the 19th and 20th century, and in the 1940s programs for children with specific learning disabilities, often referred to as brain injuries, began to become more and more common, (Wright & Wright, 2007). However, there was not set requirement for states, and the programs varied greatly both between and within states, (Wright & Wright 2007). It was with the result of the United States Supreme Court’s ruling in *Brown v. Board of Education* that changes in the education system in the United States started to be seen. *Brown v. Board of Education* states, “it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education.” *Brown v. Board of Education* ended segregation based on race within schools in the United States, and led parents of children with disabilities to “bring lawsuits against their school districts for excluding and segregating children with disabilities. The parents argued that...schools were discriminating against [their] children because of their disabilities,” (Wright & Wright 2007). People began to demand change.

In 1966 Congress for the first time addressed students with disabilities by amending the Elementary and Secondary Education Act of 1965, (Wright & Wright 2007). This amendment to ESEA put in place a grant program whose purpose was to assist states in reforming, initiating, expanding, and improving programs for handicapped students, (Wright & Wright 2007). This grant program was then replaced by Congress with the Education of the Handicapped Act in 1970. The Education of the Handicapped Act “established a grant program aimed at stimulating the States to develop educational programs and resources for individuals with disabilities,” (Wright & Wright 2007). Neither the amended ESEA nor the Education of the Handicapped Act were able to show improvements in the education of disable students, thus more reforms were needed, (Wright & Wright 2007).

As with any innovation, evaluation and reform need to be a part of the complex process of practicing and implementing the change. It was not until 1972 that Congress evaluated the laws they had put in place regarding special education. In 1972 “Congress launched an investigation into the status of children with disabilities and found that millions of children were not receiving an appropriate education,” (Wright & Wright 2007). Their findings stated, “of the more than 8 million children... with handicapping conditions requiring special education and related services, only 3.9 million such children were receiving an appropriate education. 1.75 million handicapped children [were] receiving no educational services at all, and 2.5 million handicapped children [were] receiving an inappropriate education,” (Wright & Wright 2007). It was with this evaluation Congress felt the need to create a law which ensured “that children with disabilities had access to an education and due process of law... [and] included an elaborate system of legal checks and balances,” (Wright & Wright 2007). This new law was named the Education for All Handicapped Children Act of 1975.

Over the years, special education law was amended. In 2004 Congress renamed and reformed special education law once again. This new act was named Individuals with Disabilities Education Act. The purpose of IDEA is “to provide an education that meets a child’s unique needs and prepares the child for further education, employment, and independent living... [and] protect the rights of both children with disabilities and their parents,” (Wright & Wright 2007). IDEA is able to refocus the purpose of the Education for All Handicapped Children Act to a more individually centered approach.

The Individuals with Disabilities Education Act of 2004 provides the foundation of special education today. IDEA is divided into five parts: General Provisions, Assistance for Education of All Children with Disabilities, Infants and Toddlers with Disabilities, National Activities to Improve Education of Children with Disabilities, and National Center for Special Education Research, (Wright & Wright 2007). It is with these parts, one can see how inclusive education is both defined and implemented. IDEA provides the guidelines for implementing the innovation of inclusion of students with Down syndrome.

To define the word inclusion, one may think of the act of including, bringing one person into a larger group. When we apply this definition to the words inclusive education the image of including students with disabilities in a general education classroom allows one to develop an understanding of the concept. IDEA 2004 addresses the innovation of inclusion of students with Down syndrome within its part, Assistance for Education of All Children with Disabilities. Here the requirement for a state to “educate children with disabilities with children who are not disabled, to the maximum extent appropriate,” is specified (Wright & Wright 2007). This requirement is referred to as providing students with the least restrictive environment allowed for

a student's unique needs. Providing students with the least restrictive environment means that "a child may only be removed from the regular educational setting if the nature or severity of the disability is such that the child cannot be educated in regular classes, even with the supplementary aids and services," (Wright & Wright 2007). The innovation, inclusion of Down syndrome students, is a result of providing students least restrictive environments.

Most adults have experienced exclusion at some point in their lives on the basis of race, age, sex, family background, class, sexual orientation, religion, language, or physical characteristics. The list goes on and on. Exclusion, however, is not about race or language or gender – or any other difference. Rather, the culture of exclusion posits that isolating and marginalizing the stranger, the outlier, is appropriate, acceptable, and sometimes even laudatory. Exclusion is not about difference; it is about our responses to difference.

Down syndrome is one of the most common genetic disorders with reports of one infant in every 600-800 live births. Parents are faced with two options for their child with Down syndrome when considering school placement, mainstream or special education. A mainstream classroom is described as "integration or inclusion in a regular school, often in a regular class, for part or all of a student's instructional time". A special education school or classroom is the education of students with disabilities, learning difficulties, or mental health problems in a way that addresses the students' individual differences and needs.

Inclusion in education is a philosophy based on the belief in every person's inherent right to fully participate in society. It implies acceptance of differences and access to the educational experiences that are fundamental to every student's development.

When effectively implemented, research has demonstrated academic and social benefits for all students – both those who have special needs as well as typical students. Friendships develop, typically –developing students are more appreciative of differences and students with disabilities are more motivated. True acceptance of diversity will ultimately develop within the school environment and is then carried into the home, workplace and community.

The transition to school has traditionally centered on school readiness as indicated by skill development. Such development has commonly been considered a natural consequence of chronological age at which students are determined to be eligible for school entry. More recently however, a broader view of the transition has been put forth through models that take the influence of contexts into consideration. Pianta and Kraft-Sayre (2003), for example, propose that the transition to elementary school involves different conditions, such as the school environment, teacher attitudes, family expectations and level of support provided. Thus, the transition to elementary school of children with disabilities is not only dependent on knowledge of the children's characteristics, but also on knowledge of and contributions from parents as well as health and educational systems and professionals.

As children enter school, they are expected to participate and adapt to the demands of the school and class context. Successful participation has been defined as being with others and being able to perform tasks (Heah, Case, McGuire & Law, 2007). Further, being with others and being able to achieve in activities that are valued by peers is found to be one key to social participation and friendship in mainstream school for children with Down syndrome (Fox, Farrell & Davies, 2004).

Thus, relationship with class peers take on considerable importance (Guralnick, 1999). Through performance of, and participation in everyday occupations, children learn and master new skills. From the perspective of children, doing activities together with friends is of the utmost importance (Corsaro, 1998). When children have opportunities to engage in interactions that support and strengthen their skills in naturally occurring ways in everyday life, they develop and flourish (Dunst, Bruder, Trivette, Raab, & McLeean, 2001).

In order to promote the school participation of children with Down syndrome in mainstream schools, knowledge of the child's performance of relevant activities as well as the influence of parents, peers, teachers and assistants from an occupational perspective is required. The goal of mainstream school is to allow Down syndrome students to actively participate in activities with minimal support.

In a 1999 study, children with Down syndrome attending mainstream and special education schools were compared. The comparisons were based on three categories: daily living (domestic, personal and community), socialization (interpersonal relationships, play and leisure, and coping skill), and communication (receptive language, expressive language and reading and writing) (Archer, 2006).

Research shows that the majority of the children in mainstream schools scored higher in communication skills, especially reading and writing. There was a large difference for receptive and expressive language, students that were mainstreamed score significantly higher. According to a 1992 study, students enrolled in a mainstream school were more advanced in academic attainment (Cuckle, 1998).

Curriculums are different for special education classes compared to mainstream education. Special education classes are specialized for individual needs. Each student in the classroom may have different mental capabilities and learning abilities, so the teacher reduces the academic level to make sure each student will grasp the concept (Archer 2006). Students will share stories instead of using a formal literacy lesson, meaning students are not performing at their highest academic level. Some may have higher learning abilities than others, meaning their academic achievement isn't going to rise above the student with the lowest learning ability. It is not possible to achieve a maximally effective learning environment for all students in a special education classroom (Archer, 2006)

Occupation involves what people do in everyday life, individually, or together with others. Things that people do every day change with age. Thus, when children play and perform activities of daily living, they author their own development through what they do. Skills are embedded in performance, and performance is embedded in participation (Kielhofner, 2008). Outside the family, school is a major influence on children's participation. Through participation in school activities children gain knowledge for adult life.

According to the 1999 study conducted by Sue Buckley and Ben Sacks, children in special schools achieve higher scores for daily life skills and socialization skills. This is irrelevant to schooling because life skills are mainly taught at home such as toileting, bathing, changing clothes, and cooking (Archer, 2006). Students in special schools tend to be taught in a "trainable" class where the focus isn't on academic subjects but more on self-care and independence (Rynders, 2005).

Students with Down syndrome have delayed communication skills, they scored significantly lower for expressive language and reading and writing (Archer, 2006). This is believed to happen because special schools do not focus on social and non-verbal cognitive skills and the students are surrounded by students with disabilities so learning by positive examples are extremely limited (Archer, 2006).

When an innovation is being examined from its creation stages to its implementation, a variety of perspectives can be used to help evaluate the worthiness of the innovation. With the innovation of Down syndrome inclusion, whose foundation was created by the United States Congress, the history of the innovation can help one critique the change initiative. “On any given day, the ‘system’ might not know what it is doing,” (Fullan 2007). This statement holds true when referring to the changes to special education law Congress made after the investigation they undertook in 1972. It took an investigation after years of no checks and balance system to help ensure that previously enacted laws were actually serving their original purpose. The worthiness of this innovation was able to increase after being evaluated and reformed by its creators.

The innovation of Down syndrome inclusion is one in which the school and classroom environment is greatly affected. Looking at this innovation from the perspective of those that are directly involved with the day to day school environment provides further insight into the worthiness of this innovation. Each school has both a structure and a culture. Every classroom has both a structure and a culture. Restructuring a school and a classroom in order for this innovation to be implemented would require for curriculum to be modified, a teacher to be notified, parents to be informed, and special education aids or support to be provided.

Reculturing would mean that those involved in the environments in which the student is being included not only welcome the Down syndrome student, but also understand why the inclusion is occurring and believe in the innovation of inclusion. “Restructuring (which can be done by fiat) occurs time and time again, whereas reculturing (how teachers come to question and change their beliefs and habits) is what is needed,” (Fullan 2007). Since providing least restrictive environments is a primary purpose of this innovation, considering those affected by this aspect is a crucial element in helping to reculture.

Reculturing in order to implement the inclusion of Down syndrome students in the general education classroom needs to start with providing those, including the other students in the class, involved with the meaning of the innovation inclusion and awareness of differences that may be seen among the students. “Meaning fuels motivation; and know how feeds on itself to produce ongoing problem solving. Their opposites – confusion, overload, and low sense of efficacy – deplete energy at the very time it is sorely needed,” (Fullan 2007). If meaning and awareness are not provided to both the teachers and the general education students that are also affected by the inclusion of a Down syndrome student, the culture of the classroom will suffer and the innovation will not be a success. All the students, general education and special education, all the teachers, and all others that interact in the given environment will not learn or function to their fullest ability.

As one continues to look at the innovation of Down syndrome inclusion through the perspective of those directly involved, it becomes more and more clear that reculturing the environment is the key to successful implementation of this innovation. Through reculturing of first the classroom directly involved, and then filtering the ideas and culture within that

classroom further throughout the rest of the school, and then even further into the district, true inclusion will take place. Reculturing will help district leaders, administrators, teachers, students, and parents to all feel respected and informed. Reculturing will help everyone continue to learn, and providing an effective learning environment is the goal of every school. “Clearly, students who are not respected are not motivated to learn... the same thing applies to teachers,” (Fullan 2007). Reculturing is necessary in order to show respect to all parties when implementing inclusion.

Conclusion

According to several research studies, enrolling a child with Down syndrome in a mainstream school will be the most beneficial to them in the long run. Children that were engaging with students that developed at a normal pace tended to gain more from mainstreaming than the students that were enrolled in special education school. Students that were mainstreamed had greater communication skills, academic achievements, and overall higher satisfaction from their parents. There are minimal reasons to not place a child with disabilities into mainstream classrooms. Placing a child with disabilities in a special school will reduce their interaction with typical developed children, meaning social interaction and preparation for the “real world” and independence are limited.

Enrolling a child with Down syndrome into a mainstream education classroom will also help the other students in the classroom. The Down syndrome student will improve their social and academic abilities and those without disabilities will learn to accept people with disabilities and gain a better self-worth (Rynders, 2005). Although, the initial reaction is harsh and cruel, overall most students adapt to the student in the classroom and befriend them. Peter, from

Educating Peter, is a perfect example. He was unruly and aggressive at the beginning of the school year students feared him and didn't socialize with him. By the end of Peter's year in third grade, he was accepted by everyone, and was actively participating in the classroom. One girl in the video commented, "He changed because we changed. He changed because we helped him" (Goodwin, 1992). This is a huge revelation; a third grader acknowledged that the class helped Peter be successful in his classroom because the students learned to accept him as one of their classmates.

Although, many of these studies were conducted outside the United States, the results are consistent with statistics and research done in the United States. Many of the articles written in America referenced the studies done internationally. The trend of enrolling students with disabilities into the mainstream classroom is significantly increasing with the hopes of having more people with disabilities function successfully without assistance in society.

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