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Children With Disabilities SE 2080
Service Learning Project

Case Study Paper

Charlie loves music, especially High School Musical. He loves to talk about T.V. shows, like “The Sweet Life On Deck” and “Spongebob Squarepants”. He’s very smart, quick to show friendliness, and a very sassy 16-year-old boy. Charlie also has Down Syndrome, but no one ever thinks twice about treating him differently because of it.

Down Syndrome is a condition that occurs when someone has three, rather than two, copies of the 21st chromosome. It was named after the Englishman John Langdon Down who first described the condition in 1887, though it wasn’t until 1959 that the medical world discovered the extra chromosome was the cause. No one knows why Down Syndrome is caused yet, so there is no way to prevent it. We do know that the chance of having a baby with Down Syndrome increases with the age of the mother. At age 25 the chance is 1 in 1,250 and at age 40 the chance jumps to 1 in 100. Testing the baby before it is born can give parents time to prepare, and a blood test can confirm the syndrome once the baby is born. More than 400,000 people living in the US have Down Syndrome, which alters the course of development. People with Down Syndrome are more susceptible to health complications such as childhood leukemia, congenital heart defects, hearing and vision problems, thyroid conditions, respiratory problems, and Alzheimer’s disease. The life expectancy of people living with Down Syndrome has increased dramatically from 25 in 1983 to 60 today.

Children with Down Syndrome develop at a different pace, so it is most important not to compare them to other children. They suffer from a cognitive delay ranging from mild to moderate. Some physical characteristics of people with Down Syndrome are small stature, low

muscle tone, a single deep crease across the center of the palm and an upward slant to the eyes. With that said, no two people are the same and not all people with Down Syndrome display these physical attributes. Common behavioral traits include stubborn or oppositional behavior, communication problems, wandering or running off, sleep disorders and attention problems.

Early intervention is perhaps the best thing parents can do for their child with Down Syndrome. According to the National Down Syndrome Society, “the goal of early intervention programs is to enhance and accelerate development by building on a child's strengths and by strengthening those areas that are weaker, in all areas of development”. Beginning right at birth, breast-feeding strengthens jaw and facial muscles that are needed for language. Physical therapy helps to strengthen poor muscle tone, a common trait with the syndrome. Speech and language therapy, even as simple as imitating sounds, will help a child with Down Syndrome grasp language more quickly even though many children don't make sounds until two or three years of age. Occupational therapy helps the child to master skills for independence and as they grow, to master life skills. Most importantly, parents receive encouragement, support and information. Early intervention can teach parents how to meet the specific needs of their child and help to supplement their development. Most families claim they are stronger and closer though caring for a child with Down Syndrome. Siblings tend to show higher levels of maturity, communication, and social skills. They are also more accepting and empathetic.

I worked with Charlie at the Pemi Youth Center, an afterschool program for students ages 10-17. The youth center has a structured routine, which was especially helpful for Charlie. All students had to finish homework before they were allowed to play. Charlie is smart, but has issues with communicating what he knows. I definitely noticed a learned helplessness from him when working on homework. He knows the answers but lacks the self-discipline to do it himself.

There were many volunteers at the youth center, but I noticed that Charlie was particularly attached to Chris. They have similar interests and Chris isn't afraid to give Charlie a bit of his own medicine when he's being sassy. I also noticed that Charlie was more likely to bond with male volunteers than with female volunteers. The first two weeks I didn't think Charlie liked me very much, but in the second two weeks he was much more friendly.

The most difficult part about working with Charlie at the youth center was the after school atmosphere. Charlie had a tendency to rush his homework so that he could play ball tag. Furthermore, most of the social traits he showed were more characteristic of a 16-year-old boy rather than a boy with Down Syndrome. I found it hard to decide when to fix behavioral issues because I should be treating Charlie like all the other students. What I tried to focus on was Charlie's reluctance in joining and participating in new activities.

On Thursdays the youth center activity is a group called Chain Reaction, which is a drug and alcohol awareness group run by Adventure Ed majors from PSU. The leaders of Chain Reaction do various games and activities with the students and incorporate lessons on being drug and alcohol free into their time. Charlie is very outgoing, but shy to try new things. The first week I observed we visited the Adventure Center on campus to learn about what they do and to see some rock climbing gear. Charlie was hesitant to get too close to the demonstrations and only after some intense coercing did he participate in the activities. He would only play games he wanted to play and would often sit and sulk when the group didn't play what he wanted.

A few times, Charlie just needed to watch both fellow peers and the leaders participate in an activity and he would join in. Most often he refused to do anything he didn't come up with. This was a hard call because there were five or six other students in Chain Reaction and we couldn't just stop our activity for one person. I work at a summer camp, and when a child doesn't

want to participate in an activity, they have to sit and watch. Nine times out of ten the child sees how much fun the group is having and joins in. This was the approach the leaders took with Charlie most of the time. With such a small amount of time and other students to entertain, it's nearly impossible and not fair to the others to tailor every activity to the liking of one student. If Charlie didn't join an activity at all, we would try to find one that he did want to participate in to do next. I feel that Charlie is reluctant to learn new games and try new things, which is why he is so apprehensive to join a new activity.

This observation has only further confirmed that I love working with children and would especially enjoy helping students with special needs. My aunt has Down Syndrome and I have heard many stories from my dad about growing up with her. My mom worked as a special educator for much of my life, so I have been accustomed to working children with special needs for some time now. Working with Charlie was fun and rewarding, and I very much enjoyed my time at the Pemi Youth Center.

Special Education, Third Edition. Marilyn Friend.

National Down Syndrome Society <http://www.ndss.org/>

Kids Health http://kidshealth.org/parent/medical/genetic/down_syndrome.html

National Institute of Child Health & Human Development
http://www.nichd.nih.gov/health/topics/down_syndrome.cfm