

Mainstreaming children with angelman's syndrome



**ASSIGN
BUSTER**

In 1965, Dr. Harry Angelman, a physician living in England, described three children who had characteristics which are now known to be characteristics of Angelman Syndrome.

These children all had a “ stiff, jerky gait, absent speech, excessive laughter and seizures.” (Facts 2005). At this time, Angelman syndrome was considered to be extremely rare, and there were even certain physicians who doubted its existence at all. It was not until the 1980's that many more cases came to be documented in the United States, and, interestingly, the majority of the known cases of Angelman Syndrome in America are of Caucasian origin. The incidence of Angelman Syndrome in America is estimated to be somewhere between one in 15, 000 to one in 30, 000.

(Facts 2005). Angelman Syndrome is not usually immediately recognized at birth, and the most common age for diagnosis is between three to seven years “ when the characteristic behaviors and features become most evident.” (Facts 2005). Some of the characteristics of children with this syndrome are developmental delays, speech impairments, movement or balance disorders, any combination of frequent laughter/smiling, an apparent happy demeanor, an excitable personality and very short attention span.

(Facts 2005). The seizures rarely develop before twelve months of age, and in fact, absence of seizures until the teen years is fairly common.

Hyperactivity is the most typical behavior in Angelman Syndrome, with the toddlers having “ seemingly ceaseless activity.” (Facts 2005). No one can say why laughter is so frequent in Angelman Syndrome, and studies of the

brain, using MRI or CT scans do not show any defect suggesting a " site for laughter-inducing abnormality.

" (Facts 2005). The question now is if these children can benefit from being mainstreamed into the regular public school system. It is possible, of course, and has been done, however the more extremely active AS children require special provisions in the classroom, and in general a teacher's aide or assistant is necessary to integrate the child into his classroom. Speech and communication therapy are generally considered a must, and physical therapy may offer some benefits as well. Because these children have very poor communication skills, " augmentative communication aids, such as picture cards or communication boards should be used appropriately.

" (Facts 2005). While there is a strong desire among the mental retardation educators to " mainstream as many special needs students as possible.... only about 8 percent of mentally retarded students actually attend regular schools. The majority attend schools for children with special needs; a minority are home schooled." (Mental 2005). One of the greatest benefits of mainstreaming the special needs child is that he or she has a much greater opportunity to interact with non-disabled peers, resulting in better socialization.

While public schools are not considered a " facet of community-based treatments under the 1966 act," mentally retarded students' case managers serve as the liaison between school and family, and can coordinate the therapies needed for the special needs child in public school. (Mental 2005). Joshua, a young man with Angelman's Syndrome, had a family who went

above and beyond to assure him the best life possible. They removed him from the institution that was fully covered by the state, and mainstreamed him into public school. Although both Joshua and his family will agree that the road was rocky along the way, Joshua is now a young man who lives in the family home by himself.

He values order and consistency, and those who help care for him are very aware of this need. His medical needs require him to spend a great deal of time at the hospital, and his family will say that being mainstreamed into public school gave Joshua many of the skills and capabilities needed to care for himself that they doubt he would have received had he remained in an institution for the mentally retarded. (Beach 2005). If the parents and educators involved are sympathetic to the problem, public school can indeed be one of the primary sources of help for children with Angelman Syndrome.

However, school districts across the United States vary greatly in curricula offered to meet the specific needs of these children as well as the staffing of the school to provide the necessary services. In general, the “ educational interventions,” provided by public school employees that help children with Angelman Syndrome are those that provide structure, direction and organization for the child. (Technical 2001). Each child with AS needs to be evaluated for his or her individual strengths and deficits.

One system used successfully with AS children is called Picture Exchange Communication System, which teaches the child to exchange a picture of a desired item with the teacher, who immediately honors the request. “ If one can identify a powerful reinforcement for which the child will ask, then

communication in this way is meaningful and highly motivating.” (Technical 2001). While discussing the special needs of the Angelman Syndrome child as relating to mainstreaming the child into public school, we have primarily been discussing how mainstreaming affects the special needs child only.

What we haven't discussed are the many problems in mainstreaming the AS child from both the educators' and the other students point of view.

Obviously, it is very disruptive to have an AS child in a “ normal” classroom.

Because these children have little communication skills and tend to be extremely hyperactive, as well as laughing uncontrollably many times throughout the day, clearly it is a disruption to the learning process of the other students. Few public school teachers are specifically educated in the area of special needs children, and even though the AS student may be pulled from his regular classroom for speech and physical therapy, he still spends a significant portion of each day with a teacher who is not qualified to attend to his special needs, and other children who dislike the constant disruptions caused by the AS student. The parents of the other students may have little compassion for the AS child, seeing only that the education of their own children is being compromised. In a perfect world the teacher, parents, and other students work together to create the best possible environment for the AS student, however in the real world, the pitfalls and problems are many. Parents of a child with Angelman Syndrome asked for a due process hearing at the local public school in New Hampshire, stating that the needs of their child were not being met.

The child was an eight year old, diagnosed with Angelman Syndrome as well as epilepsy, and had no formal speech and was non-ambulatory as well. The

<https://assignbuster.com/mainstreaming-children-with-angelmans-syndrome/>

attorney for the parents noted in her opening speech the absence of a Safe Feeding Plan and a Seizure Plan. " Because of student's multiple physical deficits, lack of speech, communication difficulties, fragile condition and specific safe feeding needs, it is recommended that a registered nurse be available in the classroom and for safety reasons and to administer medications." (State 2004). The attorney further emphasized the need for the Student's caregivers to be highly trained in applicable feeding procedures, and noted that transportation after eating is a concern because of the possibility of aspiration. She recommended one half hour to forty-five minutes between feeding and transporting.

The child's teacher was called on to testify, and it was obvious that this particular teacher was well educated and experienced. The teacher notes that the child appears to be happy at school and has made significant educational progress, however was definitely the most challenged of all the students in her class. The end result of the hearing was that the school was ordered to provide all medical and educational necessities for the AS child, giving him the best chance to thrive possible. While the parents were happy with the outcome of this case, I have to wonder about a school made to accommodate a severely handicapped child, which obviously would require a full time person just to attend to the child's physical needs and limitations. I'm not sure if the benefit the AS child receives from mainstreaming outweigh the negative consequences for both the school personnel and the other students in the classroom.

My personal opinion is that it is difficult if not prohibitive to mainstream children with Angelman Syndrome, even if it does offer certain benefits for the child.