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ABSTRACT

The paper examines implications of the high incidence of learning disabilities in children with Tourette Syndrome. Tourette Syndrome is a neurological disorder that causes involuntary muscle jerks and vocalizations. Approximately 60% of children with Tourette Syndrome are classified as learning disabled. It is possible that this high correlation between Tourette Syndrome and learning disability is partly the result of inappropriate educational responses to the needs of these children and the children's response to how others react to their disorder. These children may be so preoccupied with controlling their symptoms that they miss important educational input, fall further and further behind, and wind up eventually in the learning disabled category. To test this hypothesis, the mothers of three children with Tourette Syndrome were interviewed extensively about the educational progression of their child. The three case studies support the hypothesis; each of these children were placed in learning disability programs after a lag in achievement facilitated by the child's preoccupation with controlling tics. The paper stresses the importance of proper identification, the necessity of building self-esteem, and the importance of informed and sensitive teachers for children with Tourette Syndrome. (DB)

# The Evolution of Learning Disabilities in Children with Tourette Syndrome: Educational Implications*

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## Abstract

Tourette Syndrome (TS) is a neurological disorder that causes involuntary muscle jerks and vocalizations. In addition, approximately 60% of children with Tourette Syndrome are classified as learning disabled (LD). This high correlation yields significant implications for research and practice. The purpose of this paper is to discuss implications for practice. This discussion is based on the hypothesis that the high correlation between TS and LD may in part be the result of inappropriate educational responses to the needs of these children and the child's response to how others react to their disorder. To investigate this hypothesis, three case studies will be examined and discussed.

# The Evolution of Learning Disabilities in Children with Tourette Syndrome: Educational Implications

Tourette Syndrome (TS) is a neurological disorder whose symptoms are manifested before the age of 21. Symptoms include sudden involuntary body movements such as eye blinking, head jerking, shoulder shrugging and facial grimacing. This disorder is also recognized by the exhibiting of involuntary vocalizations which include throat clearing, barking noises, sniffing, grunts, echolalia and coprolalia. These involuntary movements and vocalizations are referred to as tics and any significant change in emotion (e.g., excitement, stress, anxiety, etc.) can exasperate the symptoms. Although individuals with TS can generally "control" their tics for short periods of time, results of such control may be more problematic. Delaying the exertion of tics, generally causes more severe outburst of symptoms (Bruun, 1984; Cohen, Brunn, Leckman, 1988).

In addition to a variety of tics, learning disabilities (LD) are often characteristic of children with Tourette Syndrome (Erenberg, 1986; Matthews, 1988). Estimates as high as 58% have been reported for the number of children who have learning disabilities in addition to Tourette Syndrome (Comings, 1985; Anderson, 1987; Erenberg, 1986). These startling estimates yield significant implications for research and practice. The purpose of this paper is to discuss implications for practice. Pertinent to this discussion, is a definition of learning disabilities and a review of related literature on Tourette Syndrome.

The definition of learning disabilities is currently based on behavioral manifestations that, in childhood, exhibit themselves primarily in academic performance. A child who appears to possess adequate intellectual ability but has difficulty attending, completing tasks, understanding directions, writing, listening or concentrating may cue a teacher to the possibility of an existing learning disability. In addition to academic performance, these youngsters have difficulty interacting with others, organizing themselves, and they are often very active. Such characteristics can make for a very frustrating educational experience for parents, teachers and students.

Special services tailored to meet the needs of children with learning disabilities are often sought for these individuals in an effort to help them realize success in school. Eligibility for these services is traditionally based on the documentation of a significant discrepancy between ability and achievement. Once these services are secured and an individualized educational plan is designed to meet the needs of the child, assuming this is the appropriate place, the child should realize significant gains in achievement.

Conceptually, this progression is ideal and in many cases is quite successful. However, unless all major aspects of the child's needs are addressed, the provision of such services may continue to hinder achievement. The child with Tourette Syndrome and learning disabilities is a case in point. Although many of the educational needs can be met with traditional LD approaches, inadequate and inappropriate responses to the educational needs mandated by TS can perpetuate failure.

It appears that clear distinctions need to be made regarding the primary presenting problem before an LD placement for children with TS is made. This distinction in turn should facilitate more appropriate educational alternatives. However, these distinctions may not be easily determined via traditional methods of behavior sampling and IQ-achievement discrepancy models. Although TS does not cause learning disabilities, many of the school related difficulties and the identification criteria often facilitate a learning disability classification (Hagin, 1980; Matthews, 1988).

Some of the behaviors characteristic of children with TS related to lack of achievement, include hyperactivity, distractibility, poor concentration, poor handwriting, incompletion of assignments, tests anxiety and inappropriate behavior. These behaviors are often most notable in grades 1-4 and again in early adolescence (Comings, 1985; Bornstein, 1987). Out of 250 individuals with TS, reported in Comings (1985), 54% were identified as hyperactive in the 1st and 2nd grades. Interestingly, his study also reported that tics were most severe during the second grade.

The Ohio Tourette survey (Bornstein, 1987) reported that 54.5 percent of the 772 students in their study repeated a grade during grades 1-4. This study also reported percentages of students with TS who have difficulties in certain academic areas. Among these areas are handwriting in which 43% of the population experienced difficulty, test taking 52%, meeting deadlines 47%, finishing work 45%, paying attention 59%, and concentrating 56%. These data are reflective of the general TS population (Shapiro, 1979; Comings, 1985; Bruun, 1984) and are surprisingly similar to existing LD descriptive data (Learner, 1985; Lovitt, 1989). Given these similarities, mere behavior sampling may provide insufficient information for identifying more specific educational needs.

The documentation of a significant discrepancy between achievement and ability is also problematic for determining clear distinctions between primary presenting problems and educational needs of children with TS and LD. Research indicates that individuals with TS generally score lower on standardized tests, and estimates of ability are generally inaccurate (Anderson, 1987; Ferrari, 1984; Hagin, 1980). A significant discrepancy characteristically exist between verbal and performance intelligence scores. Performance scores are often significantly lower.

Given the inadequacy of behavior sampling and discrepancy models for identifying the specific needs of TS children, a closer examination of the educational needs of these children is warranted before an LD placement is made. Children with TS and LD are currently being served in classes designed for children with LD. Their needs as individuals with TS are often overshadowed by attention to the learning disability. A careful examination of children with Tourette Syndrome may find that the learning disabilities classification may be the result of inappropriate educational responses to the needs of these children and the child's response to how others react to their disorder. This is not to say there are not TS children who have learning disabilities as a primary presenting problem. Instead it is proposed that the high correlation between the two may in part be attributed to inappropriateness of educational practices and the child's preoccupation with "control" of the symptoms to the point of missing important information. As a result, the child gets further and further behind, and the evolution of learning disabilities occurs. In support of this proposed explanation, three case studies of children with Tourette Syndrome will be examined. Discussion of these case studies will yield implications for research and will offer recommendations for more appropriate educational strategies.

The mothers of three children with Tourette Syndrome were interviewed extensively about the educational progression of their children in relation to the onset of Tourette Syndrome. Mothers were interviewed because they were more involved than the fathers, with the educational problems of the children. Questions asked of each mother are appended. The three cases were selected members of the North Carolina Chapter of the Tourette Syndrome Association. The educational and economic status of each of the families was similar. The mothers were interviewed in person and by phone. Following are the results of those interviews. The children's real names are not reported.

## Case Study I

Michael is a sixth grade student in a public elementary school. He was diagnosed when he was 9 years old and in the fourth grade. His kindergarten year was relatively uneventful and his first grade year although sprinkled with problems of attention and increased activity, ended successfully. During his second grade year of school, Michael's teacher became concerned about some head jerking tics he began to display. His mother took him to a psychologist, but no diagnosis was made. A behavior modification program was implemented and appeared to diminish the symptoms for a time. Several concerns, however, persisted through the year. Lack of attention, inability to sit in seat, constant moving about, and inconsistent performance were among the chief concerns. Michael completed the second grade year at the top of his class and was not significantly affected by the "different" behaviors he was displaying. The parent attributes this to a caring teacher who did not make a big deal out of the symptoms.

Michael's third grade year was the most pronounced with regard to the manifestation of symptomology. Michael began sniffing constantly, head jerks returned and inconsistent performance seemed to heightened. It is at this grade level that his symptoms begin to draw attention from his peers and teachers. His teachers began to comment on his behaviors. As a result Michael began to react to these responses by "trying to stop". The mother talked with the teachers on several occasions about the situation in an effort to determine the causes of such behaviors. She felt the teachers did not help the situation by constantly making reference to the "noises" he made. The teachers decided that too much pressure was being placed on Michael and as a result lowered their expectations of him. The mother expressed her disagreement with that approach, but to no avail. Michael was placed in a lower reading group, expected to do less and was not encouraged to achieve above mediocrity. Following this "demotion", the parents begin to notice a change in Michael's attitude toward school. He began to feel as though he was "weird" because he could not stop doing those "things" (i.e., tics). He started going to school daily with his top priority being not to make the noises. The parents began to see his grades slip toward the end of the year. Third grade ended tainted with some experiences that contributed to his questioning his competence and confidence.

The summer after his third grade year did not reveal any tics. However, as soon as school started a yelping tic began. He was in a new school this year but he knew the children from other settings. Because of the onset of this new tic, he started the school year spending his days trying to stop his tics. He had a very demanding teacher this year who had high expectations of him, but Michael felt he could not do the work. His parents did not know what was going on and finally took him to a neurologist who diagnosed him. Medication was recommended, but the parents were resistant to this treatment because of the possible side effects. They eventually put him on medication, however, because school was becoming unbearable. He was not finishing his work, could not pay attention, often did not know what was going on and was putting all of his energies into "stopping my tics so kids would not pick on me." His grades suffered tremendously. He went from an A/B student to a C/D student. He was finally put on medication. His parents began to see a change for the better with regard to attention and school performance. Michael spent the fifth grade year "catching up" all he had missed in the fourth grade. It was suggested that he might need special placement, but his parents refused placement. During his fifth grade year, he maintained a solid C average but did not approach school with the zeal he once had. His confidence had been broken, and he was really down on himself about what he could do and whether or not he was "normal". His parents began to see a positive change in his self concept and confidence when they began to encourage him to become involved in school activities. He entered an oratorical contest and won for the school and district. This achievement did a lot for his self esteem. His teachers began to realize he had a lot more talent than they had perceived. He moved to another school during his sixth grade year. He now has a wonderful teacher who could "not care less" about his disorder. She encourages him, understands him and has her class so organized that it is very conducive to his learning needs. Learning takes place via individualized lessons, group activity and discussion. The entire class moves about freely, learning, and discovering. In addition, she gives them projects that require that they do the presentation and coordination.

In a three month period, he has regained a lot of his confidence. He is participating in everything and hardly ever talks about his disorder. He has been on the B honor roll for the last two grading periods. Although he is having a number of tics, Michael requested that he be taken off the medication. His teacher and classmates do not seem to notice or care because there is so much happening that it does not matter. The teacher lives out her belief that all students can learn and all students are gifted. The mother feels good about his current placement and feels that this opportunity to see how talented he is will help carry him through the rest of the school years. His mother thinks he needs to have these experiences over and over again. She is keeping a log of his growth this year and plans to use it as a basis for making recommendations in future settings. Her greatest wish is that she could take his current teacher with him wherever her son goes.

## Case Study II

Langston is a 14 year old seventh grade student. He was diagnosed with TS when he was 8 years old. Symptoms were first noticed following the use of ritalin. He was in the second grade at that time. Langston repeated the first grade as a result of immaturity, problems with attention and extreme hyperactivity which got in the way of his achieving. His second grade year was disastrous. His teacher punished him by taking away those activities (e.g., physical education) that helped relieve his tics. He was punished for not completing the copying of material from the board in the allotted amount of time. His teacher constantly threatened to spank him because she felt he was doing those things on purpose and told his parents she had the right to do that with or without their permission.

The third grade year was a little better. The teacher was much more understanding and tolerant, and the aid was assigned to give him more individual one-on-one attention. He was identified as LD in the third grade but did not receive direct services because they were not available. He began receiving self-contained LD services in the fourth grade. The parents felt this was the best placement because he had gotten so far behind, and he needed more attention. His teacher in the LD class was dedicated to children and was his best teacher. He received what he needed and began to feel a little better about himself only to have progress curtailed beginning with the next school year.

His parent feels that the LD placement settled the social rejection problems he was facing, but did nothing for his academic progression. In fact, she states that he has not progressed one grade level since being placed. When asked why she keeps him in the class, she said, "Because that is the only way I can keep him from being suspended." He is constantly referred to and treated as a behavior problem in the regular class. She feels the school needs to have more well qualified teachers who understand the educational needs of these children. They need to know how to find a child's style and teach to it. Although this parent believes her son is quite capable, she feels that he will never finish high school. This is due to the lack of appropriate education, the social rejection, and inadequate provision for learning (e.g., tape recorders, calculators, etc.). She feels her son is not being taught academics and that the competency test will be a huge stumbling block. She feels later in life he will probably return to school, take up some college courses and find his own niche. She says he needs to be in a position that is not confining but allows him some flexibility to move about. She feels the school is not preparing him for a future but is trying to rid themselves of a problem. She describes his school experiences as a living hell and strongly feels that the system has failed her child.

### Case Study III

Nikki is an 8 year old, third grader who started exhibiting tics at age 5. She was diagnosed at age 6. She has not been identified as learning disabled but does receive special help in reading and is participating in an after school enrichment program to help build self esteem. Nikki is a very bright girl who fell victim to the abuse of her second grade teacher. In kindergarten, Nikki tested in the top 10% of the kindergartners entering school. Although she was a young kindergartner, she was placed in a K/1 classroom so as to assure she would be adequately challenged. At the end of kindergarten, she was reading fluently and was ready to begin in the last of the first grade reading series. First grade followed with pretty much the same achievement gains even amidst a change in school because of her parents' job transfer. Toward the end of the first grade year however, her new teacher seemed to have grown impatient with her activity, and Nikki reacted by not working as productively. Her mother stated that Nikki displayed a whole new attitude about school. This occurred in the last nine weeks in the semester, and a drop in her grades verified the change.

In the second grade she had a number of tics that began to manifest themselves. Her mother decided to observe her in class in order to document the number of tics before medication was administered. In a 50 minute period, Nikki had 202 tics. She was then placed on medication. Prior to that, her teacher had begun to punish Nikki for "acting up". Nikki's mother had discussed TS with the teacher in the beginning of the year but went again to remind her of the manifestation of this disorder. Nonetheless, this teacher continued to punish Nikki, isolated her from the class, called her retarded, and constantly humiliated her in front of the class. In addition, she removed her from the top reading group because, by her own admission, did not have time to work with her. Nikki felt it was because she was too dumb. Nikki spent the rest of her days in that class "pretending she was not in school". The mother finally had Nikki removed from this class and is seeking legal means to address this abuse. Nikki suffered tremendously. She left with no confidence. Her self-esteem was destroyed, and her academic growth was severely stunted. Nikki is currently in therapy to help overcome these problems. She lost an entire second grade year.

Nikki was moved to another school for the third grade and has a wonderful, understanding, tolerant teacher who is trying to help her get back on track. However, she is so far behind, she had to be placed in a special reading class and is grouped with the lower achieving groups. Identification and placement as LD was recommended but the parents refused, knowing the situation. The parent is encouraging her to become involved in school activities to improve her self-esteem, and it is helping. She had the main part in a school play and did a wonderful job. That really gave her a boost.

Nikki's mother is concerned that, within this year, Nikki may not be able to overcome the damage done last year. She fears that she will get another teacher who is not understanding and tolerant. If this happens again, she thinks Nikki will never regain her initial confidence and achievement. She feels Nikki needs lots of attention, love, challenges, excitement, and the flexibility of being who she is without judgment. Nikki's mother feels she has the abilities to become anything she desires. She is bright, energetic, hard working and fun to be around, but unless she is protected from the abuse and intolerance of some educators, she will never realize high achievement. She will be a discipline problem and a very, very miserable child.

## Case Study Summary and Discussion

Many other cases are available from the North Carolina Chapter of Tourette Syndrome alone, expressing the same concerns. In the North Carolina Chapter, several adolescents have dropped out of school and the parents of several others are deeply concerned that their adolescents will follow the same pattern. According to the adolescents, they cannot take any more of the teasing. They are tired of being punished for something they cannot help. They are tired of not being given the chance to learn like everyone else, and they feel as though the schools have failed them. Educators must examine the facts and seek to respond more appropriately to the educational needs of these children.

These case studies consistently show that an LD placement may not be the most appropriate placement for these students, and that the placement is often instituted because the children are behind. This lag in achievement was facilitated by preoccupation with controlling tics, response to abusive settings and lack of understanding of Tourette Syndrome. The definition of LD presented in this paper described behavioral manifestations which are very similar to behaviors exhibited by children with Tourette Syndrome. Given the overlap of behavioral symptoms, it is understandable that the specific needs of the TS child may be masked by the similarity of LD manifestations. One of the most important roles a teacher can play is to facilitate the proper identification of the TS child's needs. Until that is accomplished howeve , several other needs, common to each of these cases, needs to be discussed.

Each of the children in these cases has been hurt by the intolerance and lack of understanding of at least one teacher. In addition each has experienced rejection by teachers and peers. These childrens' self-esteem has been severely damaged as a result. Self-esteem undergirds all we become, and to destroy a child's self-esteem is to destroy his future. Considerable attention should be given to maintaining positive self-esteem in children with TS.

Two of the children in this study experienced their worst school situations in the second grade. According to Comings (1985), symptoms are most severe during the second grade year. Perhaps this information could serve to facilitate and identify inservice needs of second grade teachers. Teachers should seek to establish inviting environments for these children, especially in the earlier grades. This can be accomplished by understanding the disorder, but not making a big deal out of it and by recognizing that all people are different. The other students in the class will respond to differences according to the atmosphere established by the teacher.

Each of these children also had good experiences with at least one teacher, and this experience made a difference in the child's achievements. The common characteristic used to describe these teachers was understanding, and tolerant. "An informed and sensitive teacher can make a world of difference" (Wertheim, 1982, p. 1). Educators need to be informed and seek cooperative relationships with other school systems in order to facilitate the consistent and appropriate provision of services to these youngsters. Perhaps the option to select teachers should be exercised more often.

Finally, the case studies reveal a resistance to parental involvement. It is important that educators and parents work together in seeking to provide services for children with TS. This cooperative relationship should involve more than the mere routine, often practiced in compliance with certain mandates. Parents of children with TS are perhaps the most informed resource available to educators. They have to be because so much is still yet to be known about this disorder. To isolate the parent, perhaps, is to isolate the teacher's greatest source of information. This is not to say that teachers should not be careful of the emotional aspects that sometime get in the way of objective decisions. Barring such conflict, active parental involvement can be invaluable.

Other recommendations are inherent in these studies and should be considered when working with the TS child. Making appropriate provisions for learning such as allowing the use of calculators and tape recorders, opportunity for physical activity, reduction of stressful situations, involvement in school activities, recognizing the child's capabilities and a sincere desire to help, are among many suggestions that can facilitate the appropriate provision of services for children with Tourette Syndrome. Careful attention should also be given to possible side effects of medication such as ritalin. Given the relationship to the onset of tics, medications should be cautiously recommended and carefully monitored.

This paper sought to communicate the importance of proper identification, necessity of building self-esteem, and the importance of informed and sensitive teachers in the lives of children with Tourette Syndrome. Many individuals with Tourette Syndrome are leading productive, successful lives. An appropriately responsive education system is the means to achieve successful experiences for all children with TS. The parent's willingness to share their stories will be well worth it if just one teacher responds to a TS child in a more informed and more sensitive way.

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## Appendix

### Interview Questions

1. How old is your child now?
2. When was he diagnosed with TS and what lead to the diagnosis?
3. Is your child receiving services as LD or other special services?
4. What lead to the identification of your child as LD?
5. Describe your child's school experiences.
6. What was the worst school year and why?
7. What was the best school year and why?
8. Has your child repeated any grades?
9. Do any teachers stand out in your mind and for what reason.
10. How have the LD services helped or hindered your child and why?
11. What do you feel your child needs?
12. What are your gut feelings about his potential?
13. Is he teased by others and how does he respond.
14. What changes would you like to see in services?
15. How do you feel your child will turn out (i.e., finish school, etc.)?