



## LESSONS LEARNED:

## TSA AND THE IDEA

### Lesson 1: NO ONE CAN AFFORD TO BE COMPLACENT

The Individuals with Disabilities Act (IDEA) was originally passed by Congress in 1975. To say that it revolutionized the educational opportunities for children with TS is an understatement. The law gave parents of school age children the muscle they needed to get the accommodations that enable many children with Tourette Syndrome, (OCD, ADD and/or ADHD) to get the education that every child deserves. The IDEA also made it possible for adults with TS to further their educations, mandating necessary accommodations that opened up universities and colleges around the country.

Twenty-eight years later, on March 19, 2003, H.R. 1350, a bill entitled, "Improving Education Results for Children with Disabilities Act of 2003" was introduced by the Republicans in the House of Representatives. This bill was designed to reauthorize the IDEA, while updating portions of its content. On April 2, the House Education Reform Subcommittee made changes in the law and passed it by a voice vote. Later that month the House Education and Workforce Committee made additional changes and approved the bill.

At first glance, reauthorization of a successful piece of legislation is good news. But the updated passages changed the way IDEA had worked for students with TS. The new version of the IDEA contained a section on discipline that could be a minefield of problems for a child with TS. One item called for the automatic removal from school of a child who inflicts serious bodily injury.

To people unfamiliar with the manifestations of TS that include involuntary movements and the potential for an accidental injury, immediate removal from school of a child who has injured another student seems sensible. But when TS is

understood correctly, it's reasonable to investigate the circumstances of the injury before removing a child for what might be the unfortunate results of an involuntary action.

The new bill contained passages that could reverse much of the good of the original IDEA by lowering tolerance of the very behaviors that characterize the symptoms of TS, OCD, ADHD, etc. Children unable to sit still, who have verbal and or physical tics, who have difficulty with eye tracking and holding a pencil, who have limited attention spans or who are plagued with obsessive thoughts, require a tolerant educational environment in order to learn—not one that demands unilateral compliance. Zero tolerance for "bad" behavior sounds good on paper, but it has unintended consequences.

The story of the IDEA is even more complicated by the nature of legislation. The Senate version of the reauthorization

bill (S. 1248) is over 800 pages long. Throughout the bill references are made to other sections of the bill or to the United States Code. In order to truly understand the language, a reader must follow the references back and forth. For example, in section (K), which discusses discipline, readers are sent to the United States Code for a definition of "serious bodily injury."

### Lesson 2: WORK TOGETHER

Fortunately for everyone with TS, there are individuals and groups who monitor legislation, and have the facilities to read and understand the implications of each clause. TSA has a Government Relations office in Washington D.C. and is a member of the Consortium for Citizens with Disabilities Task Force (CCD).

On April 29, the CCD organized visits to every member of the House of

continued on page 6

## TIM HOWARD STARS FOR TS AS GOALIE FOR MANCHESTER UNITED

Tim Howard, already a familiar figure to soccer fans as the goalie for the New York/New Jersey MetroStars, was introduced to the TSA family in this newsletter in the Spring of 2002. Tim is now the goalkeeper for the world famous British team—Manchester United. As a superb athlete and member of a winning team, Tim will be a role model for children with TS around the globe.

Howard's motto on TS is, "never let it be a stop sign, it's just a speed bump—another obstacle to overcome."

The British tabloid press, not known for moderation or accuracy, had a field day with Tim's TS. They sensationalized his condition with puns and jokes about foul language, spreading misinformation with headlines like: "Howard a Goalkeeper to Swear By," "We Swear It's True," "Tourette's Sufferer is Target for United," "United Swear By Star Goalkeeper," and "United's Swearing Savior."

continued on page 10

