No. 07-1178

IN THE

Supreme Court of the United States

JOEL HJORTNESS, A MINOR, BY AND THROUGH HIS
PARENTS AND LEGAL GUARDIANS ERIC HJORTNESS
AND GAIL HJORTNESS, ERIC HJORTNESS,
AND GAIL HJORTNESS,
Petitioners,
v.
NEENAH JOINT SCHOOL DISTRICT,
Respondent.

Petition for a Writ of Certiorari
to the United States Court of Appeals
for the Seventh Circuit

MOTION OF TOURETTE SYNDROME ASSOCIATION, INC. FOR LEAVE TO FILE A BRIEF AS *AMICUS CURIAE* IN SUPPORT OF PETITION FOR A WRIT OF CERTIORARI, AND BRIEF ATTACHED

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STATEMENT

The Tourette Syndrome Association, Inc. ("TSA") hereby respectfully moves for leave pursuant to Rule 37 of the Rules of the Supreme Court of the United States to file the attached brief, *amicus curiae*, in support of the petitioners Joel Hjortness, a minor, by and through his parents and legal guardians Eric Hjortness and Gail Hjortness, Eric Hjortness, and Gail Hjortness. Attorneys for petitioners consented thereto. The consent of the attorney for respondent was requested but refused.

THE *AMICUS* AND ITS INTEREST

TSA is the national non-profit organization dedicated to assisting persons living with Tourette Syndrome ("TS"). TSA's mission is to identify the cause of, find the cure for, and control the effects of TS. TSA educates parents of youngsters with TS about the complex nature of TS and its co-morbid neurobiological conditions, and also offers resources and referrals to help people with TS and their families cope with the many issues associated with TS. TSA strives to raise public awareness about TS and works to correct the inaccurate media and public stereotypes about TS. TSA also endeavors to educate teachers, medical professionals, and other professionals about TS. TSA's membership includes, among others, individuals, families, relatives, doctors, scientists, and other professionals working in the field. Since its founding, TSA has grown into a major national health-related organization with 31 chapters in the United States, one regional office, 125 support groups, and contacts around the world.

The interest of *amicus* reflects the essential need of children with TS to have their parents explain their complex disability and advocate their unique needs to educators who are deciding how to best educate these children, as well as the right of those parents to collaborate in making the best and appropriate choices for these children. TSA's brief will demonstrate how the substantive and procedural safeguards of the Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1400 *et seq.*, play an indispensable role and provide a vital benefit to children with uncommon, complex, and often misunderstood disabilities such as TS. Children with TS enjoy the protections of these safeguards – provided they have the good fortune to live within the jurisdiction of the Third, Fourth, Sixth, and Ninth Circuits. TSA is concerned for children with TS living within the jurisdiction of the Seventh Circuit whose decision below turns these valuable and meaningful protections into mere formalities.

Unless this Court reverses the Seventh Circuit and reaffirms the importance of the IDEA's substantive and procedural safeguards, children with uncommon, complex and often misunderstood disabilities such as TS will be deprived free and appropriate educations.

In light of the foregoing, TSA respectfully requests leave to file the attached brief.

Respectfully submitted,

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Dated: April 15, 2008

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BRIEF OF TOURETTE SYNDROME ASSOCIATION, INC., AS AMICUS CURIAE, IN SUPPORT OF PETITION FOR A WRIT OF CERTIORARI

STATEMENT

The Tourette Syndrome Association, Inc. ("TSA") submits this brief, *amicus curiae*, in support of the petitioners Joel Hjortness, a minor, by and through his parents and legal guardians Eric Hjortness and Gail Hjortness, Eric Hjortness, and Gail Hjortness, having submitted a motion for permission to file same.[1]

THE *AMICUS* AND ITS INTEREST

TSA is the national non-profit organization dedicated to assisting persons living with Tourette Syndrome ("TS"). TSA's mission is to identify the cause of, find the cure for, and control the effects of TS. TSA educates parents of youngsters with TS about the complex nature of TS and its co-morbid neurobiological conditions, and also offers resources and referrals to help people with TS and their families cope with the many issues associated with TS. TSA strives to raise public awareness about TS and works to correct the inaccurate media and public stereotypes about TS. TSA also endeavors to educate teachers, medical professionals, and other professionals about TS. TSA's membership includes, among others, individuals, families, relatives, doctors, scientists, and other professionals working in the field. Since its founding, TSA has grown into a major national health-related organization with 31 chapters in the United States, one regional office, 125 support groups, and contacts around the world.

The interest of *amicus* reflects the essential need of children with TS to have their parents explain their complex

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[1] No counsel for a party authored this brief in whole or in part, and no such counsel or party made a monetary contribution intended to fund the preparation or submission of this brief. No person other than *amicus curiae*, its members, or its counsel made a monetary contribution to its preparation or submission. The Petitioners have consented to the filing of this brief and both parties have been given at least 10 days notice of *amicus'* intention to file. Sup. Ct. R. 37.6.

disability and advocate their unique needs to educators who are deciding how to best educate these children, as well as the right of those parents to collaborate in making the best and appropriate choices for these children. TSA's brief will demonstrate how the substantive and procedural safeguards of the Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1400 *et seq.*, play an indispensable role and provide a vital benefit to children with uncommon, complex, and often misunderstood disabilities such as TS. Children with TS enjoy the protections of these safeguards – provided they have the good fortune to live within the jurisdiction of the Third, Fourth, Sixth, and Ninth Circuits. TSA is concerned for children with TS living within the jurisdiction of the Seventh Circuit whose decision below turns these valuable and meaningful protections into mere formalities.

Introduction

TS manifests itself in a multitude of different ways and in various times in different individuals. TS is a neurological disorder which becomes evident in early childhood or adolescence between the ages of 2 and 8. TS is defined by multiple tics – sudden, repetitive, non-rhythmic, and involuntary movements (motor tics) and/or sudden repetitive, non-rhythmic, involuntary utterances (vocal tics) – that last for more than one year. TS usually first presents itself through involuntary motor tics in the face, arms, limbs or trunk. The most common first symptom of TS is a facial tic such as an eye blink, nose twitch, or grimace. Subsequently, these initial symptoms are replaced or added to by the expression of other tics of the neck, trunk, and limbs. Tics may also be more complicated and for some, involve the entire body in actions such as kicking, stamping, or jumping.

Verbal tics or vocalizations occur with the motor tics. Verbal tics may include vocalizations such as grunting, throat clearing, shouting, or barking.

Despite widespread publicity, the involuntary use of obscene or socially inappropriate words or phrases (coprolalia) and gestures (copropraxia) are uncommon with TS. Neither coprolalia nor copropraxia are necessary for a diagnosis of TS.

Although some people with TS report what are described as premonitory urges (i.e., a very brief feeling right before expressing their motor or vocal tics), it should be understood that all tics are involuntary and thus outside the person's control.

Other symptoms of TS may include "Echo phenomena" such as repeating words of others (echolalia), repeating ones own words (palilalia), or repeating the movements of others. TS is frequently comorbid with other conditions such as Attention Deficit & Hyperactivity Disorder, Oppositional Defiant Disorder, Obsessive-Compulsive Disorder, impulsiveness, and various learning disabilities.

Although the symptoms of TS vary from person to person and range from very mild to severe, the majority of cases are mild. TS and other tic disorders occur in all ethnic groups. Males are affected 3 to 4 times more often than females.

Most people with TS and other tic disorders lead productive lives. There are no barriers to achievement in their personal or professional lives and persons with TS can be found in all professions. One goal of TSA is to educate both patients and the public about the many facets of tic disorders. Increased public understanding and tolerance of

TS symptoms are of paramount importance to people with TS and to the TSA.

Because of the significant social and emotional impact of coping with TS in school-age children, it is important that this social and emotional impact not be aggravated by unnecessary school difficulties. The IDEA plays an indispensable role and provides a vital benefit in helping students with TS obtain an appropriate education. However, as more fully discussed below, when parents are denied the opportunity to meaningfully participate in the creation of their child's individualized education plan ("IEP") and when schools are allowed to make placement decisions before an IEP meeting has taken place, students with TS, as well as other disabilities, are stripped of the vital benefits to which they are entitled under the IDEA.

ARGUMENT

REAFFIRMING THE STATUTORY MANDATE THAT A SCHOOL DISTRICT MAY NOT PREDETERMINE A DISABLED CHILD'S PLACEMENT BEFORE THE IEP MEETING WITH THE PARENTS AND THE SUBSEQUENT FORMULATION OF AN IEP TAILORED TO THE UNIQUE NEEDS OF THE SPECIFIC CHILD IS OF PARTICULAR IMPORTANCE WHEN THE NATURE OF THE DISABILITY IS COMPLEX, MISUNDERSTOOD, AND NOT GENERALLY WELL-KNOWN.

The IDEA lists its purposes in the statute. The first two listed purposes are:

> (1)(A) to ensure that all children with disabilities have available to them a free

> appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living;
>
> (B) to ensure that the rights of children with disabilities and parents of such children are protected;

§ 1400(d)(1)(A) and (B).

These purposes recognize both the unique needs of each and every child with a disability and the significant role the parents play in the lives of those children. Toward that end, the IDEA contains mandatory provisions to effectuate these purposes with the goal of providing each child with a "free appropriate public education." This education must be "specially designed … to meet the <u>unique</u> needs of a child with a disability," (§1401(29) (emphasis added), and may take place in the regular public school system or, if appropriate, at a private school or facility. § 1412(a)(10).

This Court has recently described the procedure for the development of the IEP to match the child's unique needs:

> IDEA requires school districts to develop an IEP for each child with a disability, see §§ 1412(a)(4), 1414(d), with parents playing "a significant role" in this process. Parents serve as members of the team that develops the IEP. § 1414(d)(1)(B). The "concerns" parents have "for enhancing the education of their child" must be considered by the team. § 1414(d)(3)(A)(ii). IDEA accords parents additional protections that apply throughout the IEP process. See, *e.g.*, § 1414(4)(A)

> (requiring the IEP Team to revise the IEP when appropriate to address certain information provided by the parents); § 1414(e) (requiring States to "ensure that parents of [a child with a disability] are members of any group that makes decisions on the educational placement of their child"). The statute also sets up general procedural safeguards that protect the informed involvement of parents in the development of an education for their child. See, *e.g.*, § 1415(a) (requiring States to "establish and maintain procedures … to ensure that children with disabilities and their parents are guaranteed procedural safeguards with respect to the provision of a free appropriate public education"); § 1415(b)(1) (mandating that States provide an opportunity for parents to examine all relevant records). See generally §§ 1414, 1415. A central purpose of the parental protections is to facilitate the provision of a " 'free appropriate public education,' " § 1401(9), which must be made available to the child "in conformity with the [IEP]," § 1401(9)(D).

Winkelman ex rel. Winkelman v. Parma School Dist., 127 Sup. Ct. 1994, 2000 (2007).

The procedure described in Winkelman was not followed in this case. As found by the Administrative Law Judge (whose findings were not overturned by the district court or court of appeals), the conclusions of the IEP and the placement decision were pre-determined, thus denying the parents "meaningful participation" in the IEP and placement processes. (Pet. For Writ of Cert., App. C, 56a.) Moreover, the Administrative Law Judge found that the IEP contained numerous goals that were not discussed at the IEP meeting and was finalized by drafters "without assistance from the IEP team." (Pet. For Writ of Cert., App. C, 64a.)

Additionally, as set forth by petitioners in their petition and in the opinions of the Third, Fourth, Sixth, and Ninth Circuits[2], the IDEA requires that the determination of the appropriate school placement for a child with disabilities must follow the promulgation of and be based on the goals of an IEP that has been previously developed with the child's parents' input.

This statutorily mandated timing makes good sense. Teachers and school administrators see and interact with students with disabilities for only part of the day and in a single venue; a venue which, for children with TS, may well be particularly stressful. The IEP meeting with parents provides school officials with an essential and incomparable window into the daily life, individual characteristics, strengths, and struggles of the child. Parents possess a wealth of information, gathered over the child's entire lifetime, giving them the most relevant and most comprehensive information on which the IEP should be based.

This is particularly true and necessary where, as here, the student's disability is neurological and, at least as to its TS component, not well-known and often misunderstood. By their nature, neurologically-based disabilities are

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[2] Fuhrmann ex rel. Fuhrmann v. E. Hanover Bd. of Educ., 993 F. 2d 1031 (3d Cir. 1993); Spielberg ex rel. Spielberg v. Henrico County Pub. Sch., 853 F. 2d 256 (4th Cir. 1988) (under predecessor statute); Deal v. Hamilton County Bd. of Educ., 392 F. 3d 840 (6th Cir. 2004); W.G. v. Bd. of Trs., 960 F. 2d 1479 (9th Cir. 1992); See also Schoenbach v. Dist. of Columbia, No. 05-1591, 2006 WL 1663426 (D.D.C. June 12, 2006).

particularly difficult to analyze because their causes and effects are not physically visible.[3] Additionally, the symptoms of TS vary between individuals and may not be constant or regular in the same individual over the course of time – with differences ranging from minor motor and vocal tics to loud and offensive verbal outbursts. To be effective, the development of IEPs and subsequent placement decisions must be based on each individual student, not on classes of disorders, preconceived notions about disorders, or even a student's IEP developed for a previous school year.

It is not known precisely how many persons have TS, but epidemiological studies indicate that the number of affected children is estimated at 250,000.[4] Those who are not well acquainted with TS – including many teachers and school officials – often assume that, if the person with TS "really tries," he or she can stop or control their motor and vocal tics. IEPs should not be developed and placement decisions should not be made without such preconceived notions being corrected and addressed by the student's parents.

The IDEA does not distinguish among disabilities. Thus, while compliance with the mandated procedures of the IDEA is universally applicable and legally required, the failure to comply is particularly harmful to the interests of the

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[3] The difficulty is compounded when, as is often the case, the child has a number of overlapping neurological conditions. Thus, in this case, the ALJ found that Joel Hjortness had been diagnosed with severe behavioral and emotional disabilities, including at various times "obsessive compulsive disorder, Tourette's disorder, attention deficit/hyperactivity disorder, autistic spectrum disorder, oppositional defiant disorder, and anxiety disorder." (Pet. For Writ of Cert., App. C, 39a.)

[4] Scahill, L., Williams, S., Schwab-Stone, M., Applegate, J. Leckman, J.F., 2006; *Advances in Neurology*, vol.99: pp184-190.

child, for whose benefit the IDEA was passed, when determining the “unique” requirements of a child with a neurological disorder such as TS.

CONCLUSION

Congress, in drafting the IDEA, recognized the necessity of, and required, a broadly scoped examination of the unique disabilities of the individual child jointly by parents and school officials and the development of an individualized IEP based on that examination. Further, children are likely to be deprived appropriate educations when school placement decisions are made before the IEP has been properly developed. *Amicus* TSA urges that the petition for a writ of certiorari be granted so that the intent of Congress and the language of the IDEA may be upheld.

Respectfully submitted,

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CERTIFICATE OF COMPLIANCE

As required by Supreme Court Rule 33.1(h), I certify that the document contains 2,677 words, excluding the parts of the document that are exempted by Supreme Court Rule 33.1(d).

I declare under penalty of perjury that the foregoing is true and correct.

Executed on April 15, 2008.